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ACCESS TO EVERYDAY ACTIVITIES IN PUBLIC SPACE

Views of people with dementia

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ABSTRACT

The general aim of this thesis was to increase knowledge about problematic situations in public space as experienced by community-dwelling people with dementia, and about how they meet these situations when doing everyday activities there. The aim also included increasing knowledge about transactions between people with dementia and public space.

In **Study I** experiences of accessibility in public space in people with AD were illuminated, with particular focus on places, situations and activities that they found important for daily life. **Study II** discovered and described problematic situations and critical incidents that took place when people with AD performed grocery shopping, and how these incidents were met by them. **Study III** identified characteristics of the space of a grocery shop and how these characteristics meet the prerequisites of people with dementia. **Study IV** identified problematic situations at zebra crossings in roads, and how people with dementia would understand, interpret, and act in these problematic situations based on their previous experiences, and linked to the film sequences.

The findings of **Study I** showed that accessibility was experienced as a constantly changing experience, characterized by changes in the relationship between the public space and the informants. Changes in the relationship occurred in use of place and activities and related to comfort and familiarity, interests and motives and protecting and planning. Other changes occurred in problematic situations related to crowded places with high noise and tempo, everyday technologies and change of landmarks. A challenging and unstable process of meeting critical incidents was the core category of **Study II**. The informants used creativity and reflection to achieve relative harmony in each critical incident. The critical incidents and actions to meet these when doing grocery shopping were described in the categories of remembering to bring things when leaving home, finding the way to and from the grocery shop without getting lost, finding a way through traffic when not feeling safe, finding objects when organization is disrupted, choosing when several objects and products are available and finding a method to pay when payment opportunities are restricted. In **Study III** a variety of characteristics that could influence if a shop was experienced as accessible was found: stressors, colour and auditory stimuli, information overload, spatial issues, layout variations and visual illusions. The core category of multi-faceted and multi-sensory crowding and clutter described the informants' prerequisites and the shop's characteristics. These were related to each other and influenced how the person with dementia coordinated with the place. In **Study IV**, problematic situations were illuminated when informants crossed a street with or without a traffic light. The situations became problematic when layers of the problematic situations were added to each other and created a problematic situation as a whole. These layers were related to vehicles and crowding of pedestrians, weather conditions, design and layout of streets and zebra crossings. The informants experienced difficulties in coordinating with the problematic traffic situation as a whole. The actions they used were to avoid problematic situations, use traffic lights as reminders and security precautions, follow the flow at the zebra crossing and be a cautious pedestrian. In the core category – the hazard of meeting unfolded problematic traffic situations when only one layer at a time can be kept in focus – the constant interplay was described.

This thesis presents new knowledge about problematic situations related to grocery shopping and being a pedestrian for people with dementia. Common characteristics of problematic situations in these activities were related to unpredictable changes, crowding and clutter and layout variations. The thesis also offers new knowledge about how they met these situations with different actions, and how the process worked to meet problematic situations that came to the fore. Their actions were characterized by using time, using familiar activities in familiar spaces and places, avoiding situations leading to new problematic situations and getting help from people. Furthermore, new knowledge was developed about the relationship between persons and environments by using a transactional perspective. The knowledge of how people with dementia access activities in public space could be translated into clinical practice for supporting people with dementia doing activities in public space, and for creating a more accessible and usable public space on a societal level.

Key words: activities of daily living, aging, critical incident technique, crowding, dementia, environment, grocery shopping, grounded theory, pedestrian, traffic safety, transactionalism.

LIST OF PUBLICATIONS

This thesis is based on the following publications, referred to in the text as studies by their roman numerals:

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LIST OF ABBREVIATIONS

AB	Anna Brorsson
AD	Alzheimer's disease
ADL	Activities of daily living
CIT	Critical Incident Technique
CMOP	Canadian Model of Occupational Performance
IADL	Instrumental activities of daily living
MMSE	Mini Mental State Examination
MOHO	Model of Human Occupation
PEOP	Person-Environment-Occupational Performance model
SL	Stefan Lundberg
FTD	Frontotemporal dementia
NINCDS-ARDA	National Institute of Neurological and Communicative Disorders and Stroke- Alzheimer's Disease and Related Disorders Association

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PERSONAL INTRODUCTION

My interest in accessibility issues was raised during my training as an occupational therapist, and my intention was to work with issues concerning people and the environment. My career as an occupational therapist led me into different areas of work. I worked primarily in a geriatric rehabilitation unit, but interest in the environment and the person has always been in my mind and reflected in my practice. For example, when the ward where I worked was renovated I had the opportunity to influence accessibility.

As an occupational therapist I had the knowledge of how to adapt the environment by means of home modifications and assistive devices. To some extent an occupational therapist can influence accessibility and facilitate participation in everyday activities in public space. But in my clinical experience the public space is commonly seen as the nearby neighbourhood, and interventions are limited to enabling the person to get in and out of the house and walk around in the nearby surroundings. Activities in public space are often addressed only by oral information about hobbies and interests. By using this limited approach a great deal of understanding and knowledge about public space and activities is lost. Therefore I think the view of public space must be broadened. If public space is going to be incorporated into everyday life, more research is needed about how people experience accessibility and usability and how they manage everyday activities in public space. In order to create a more accessible and usable public space, especially for people with dementia, new knowledge in occupational therapy must be developed, as we so far have mostly been paying attention to physical accessibility.

My interest in research began during research for my master's thesis and grew stronger and stronger during that period. I had the great privilege of becoming a PhD student in this project, with the focus on accessibility and people with dementia doing everyday activities in public space. This was in line with my beliefs that public space must be acknowledged as part of the life world of people with disabilities, and that it be given increased attention in occupational therapy when people age and stay in their ordinary housing for a long time with or without disabilities, and consequently also need to do activities in public space.

INTRODUCTION

Accessibility issues in public space have received attention thanks to different disability groups and because of the growing number of elderly persons in the community (Burton, 2006). Accessibility in public space has mainly been viewed from a physical perspective and with the focus on people with physical disabilities (Imrie & Kumar, 1998). In contrast, knowledge is very sparse about accessibility for persons with cognitive disorders such as dementia and stroke (Blackman et al., 2003). This seems remarkable when the aim is that older people should remain living in their communities and homes as long as possible, i.e. age in place (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012). The elderly population with dementia will increase (Wimo, Winblad, & Jönsson, 2007) and is estimated to rise to 81.1 million worldwide in 2040 (Ferri et al., 2005). In Sweden the number of people with dementia was approximately 148 000 in 2010, and around half of them were living in ordinary housing on their own (*National Guidelines for Care in Cases of Dementia*, 2010). Simultaneously with the increasing number of people with dementia, the complexity in public space increases due to developments like services being automatised in shops and health care facilities (Emiliani, 2006; Jensen, Iwarsson, & Ståhl, 2002). The increased complexity in public space places new demands on the inhabitants regarding cognition (Nygård, 2008; Nygård & Starkhammar, 2007), but the competence of people with dementia will of course not increase (Nygård & Winblad, 2006), as the disease is progressive (APA, 2000). Furthermore, having access to everyday activities is associated with health and social benefits and if the public space is avoided by people with dementia it is likely to influence their health status (Blackman et al., 2003). However, there is a lack of knowledge about accessibility obstacles that might be experienced by people with cognitive disorders such as dementia doing everyday activities in public space. The general aim of this thesis is to increase knowledge about problematic situations in public space as experienced by community-dwelling people with dementia, and how they meet these situations when doing everyday activities. The aim also includes increasing knowledge about transactions between people with dementia and public space.

BACKGROUND

Theoretical framework

The thesis has its theoretical framework in occupational therapy and occupational science, complemented with elements from the medical field to describe consequences of dementia related to everyday activities. The views of people with dementia doing everyday activities in public space are in the foreground. This perspective is not new; it has become increasingly common to include people with cognitive disorders in qualitative research (Hubbard, Downs, & Tester, 2003; Kitwood, 1997). In occupational therapy research the focus has been on their views on everyday activities (Nygård, 2006; Öhman, Josephsson, & Nygård, 2008). However it is worth noting that the shift in perspective came only in the 1990s (Hubbard et al., 2003). The focus was earlier on biomedical aspects of dementia (Kitwood, 1997), and people with dementia were regarded as incapable of sharing their experiences verbally (Hubbard et al., 2003). In the following the occupational perspective based on transactionalism and the concepts of place integration and problematic situations will be introduced. The concepts of place, space, accessibility and usability will also be described.

An occupational perspective based on transactionalism

This thesis focuses on people with dementia living in ordinary housing who thereby also encounter activities in public space. To understand how they experience access to everyday activities in public space, an occupational framework has been applied in the four studies.

The core beliefs in occupational therapy are that there is a relationship between health and involvement in occupations and that people are viewed as occupational beings (Law, 2002; Occupational Therapy Practice Framework: Domain & Process 2nd Edition, 2008). In occupational therapy the term “occupation” is used to capture the meaning and breadth of everyday activity (Occupational Therapy Practice Framework: Domain & Process 2nd Edition, 2008).

In this thesis the transactional perspective on occupation is used, based on the theories of philosopher John Dewey. In this view occupation is viewed as meaning-rich human actions, emergent, holistic and contextual (Shank, 2012). Occupation can be viewed as

a transaction linking the situations and the person, and therefore the person and the environment are parts of each other; that is, occupation is the glue between the individual and environment (Cutchin, Aldrich, Bailliard, & Coppola, 2008).

There are many different definitions of “occupation” and in this thesis the word “occupation” is not used. Instead “activity” has been used to describe participation in daily life pursuits (Occupational Therapy Practice Framework: Domain & Process 2nd Edition, 2008), i.e. activity is synonymous with occupation in this thesis. This decision is based on the fact that literature within the area of public space and accessibility commonly uses the term activity, hence activity is assumed to facilitate communication of knowledge.

The transactional perspective is based on the theory of action that has become known as transactionalism (Cutchin & Dickie, 2012). This approach is relevant for knowledge development regarding elements like inclusion, participation, social justice and environmental concerns (Cutchin & Dickie, 2012), in other words making a better world for people with dementia as being a part of the public space. The transactional perspective has until very recently not been incorporated into occupational therapy research (Dickie, Cutchin, & Humphry, 2006), but a shift has taken place and today the perspective is more often used (Dickie, 2010; Eriksson, Park, & Tham, 2010; Johansson, Cutchin, & Lilja, 2013; Johansson, Josephsson, & Lilja, 2009; Nyman, Josephsson, & Isaksson, 2013; Rosenberg, Kottorp, & Nygård, 2012; Shank & Cutchin, 2010).

The transactional perspective is based on a holistic and non-dualistic view of relations, meaning that entities are parts of each other instead of being separate from each other. In the transactional view the places that persons transact with are not just about physical forms. They also include political, cultural and social aspects. The transactional relations also include spatial and temporal dimensions (Dickie et al., 2006). The purpose of transactions is to *“functionally coordinate relations to keep the transactional unit whole and operational, for the benefit of the dimensions that constitute it”* (Dickie et al., 2006, p.90). In the transactional view the body is not a static capsule of individual, physical elements, but a person inhabiting the world in a dynamic process (Aldrich & Cutchin, 2013).

The transactional perspective challenges general occupational therapy theories concerning the person and the environment. One common way of explaining and understanding the environment is to use demand and press components. Press is described to represent different characteristics in the environment that place demands on the person to respond (Stewart & Law, 2003). Another aspect that has been questioned is that the person and the environment often are separated from each other in occupational therapy theories. This is seen in the Canadian Model of Occupational Performance (CMOP) (Law et al., 1996), where the environments occur outside the person and are influenced by the behaviour of the person. But at the same time the environment, person and occupation is said to interact continually across space and time in ways that decrease or increase their congruence (Law et al., 1996; Stewart & Law, 2003).

In the same way, the Model of Human Occupation (MOHO) (Kielhofner, 2008) separates the persons and the environments from each other. In the MOHO, environmental impact is emphasized, in terms of constraints and demands that the environment has on the individual (Kielhofner, 2008). Finally, in the model of Person-Environment-Occupational Performance (PEOP) (Baum & Christiansen, 2005), the major assumptions about the environment are that it creates expectations and demands for occupational behaviour (Baum & Christiansen, 2005).

In the models described above, the environment is viewed as a container in which people exist and perform activities (Cutchin, 2004) and the environment sets demands and press, and enables or impacts performance (Baum & Christiansen, 2005; Kielhofner, 2008; Law et al., 1996)}. In this dualistic view, the person and the environment are viewed as separate units. But at the same time it is emphasized that the environment is a part of the person (Kielhofner, 2008). Today there is a shift away from single environmental solutions to a more holistic approach (Calkins, 2001). The benefits of using a transactional perspective is that it allows us to step away from the dualistic view of person and environment with the focus on environmental press and capacities of the person, and to introduce a more holistic approach. This approach facilitates the understanding of the relationship between the person and environment and goes from simplicity to complexity (Cutchin, 2004).

Place integration and problematic situations

In this thesis the wording *meeting or managing problematic situation with different actions* is used instead of concepts such as coping or adaptation, as the latter are based on a more dualistic view. Action is an important concept in the transactional perspective and transactions are seen in a holistic view, i.e. the person and the environment cannot be separated from each other (Dickie et al., 2006).

The concept of situation has its background in symbolic interactionism, and is very important. The situation is in a constant state of change and thus when the situation changes the person's behaviour will also change. The person perceives and defines the whole situation in both a conscious and an unconscious way and acts in relationship with the environment (Trost & Levin, 2010).

In the transactional perspective the focus is on problematic situations (Cutchin & Dickie, 2012). Problematic situations are the basis of human action, initiating how people coordinate with their environment (Cutchin, 2004). Place integration is a concept based on a combination of the philosophy of John Dewey and geographical theory (Cutchin, 2001). Place integration is the ongoing process of establishing relative harmony and new meanings in new situations (Cutchin, 1997, 2001). The ongoing transaction is characterized by change and instability (Garrison, 2001) and is not always successful (Cutchin, 2013). The actions used to establish harmony in the situations is based on intelligent action that has aesthetic, moral and social bases, and the process is ongoing (Cutchin, 2004). Most often people coordinate with their environment by restructuring the environment rather than personally adapting it (Cutchin & Dickie, 2012). The goal of place integration is to attain the best harmony possible and new meanings for the situations and actor. The process of place integration is ongoing and never completed (Cutchin, 2003, 2004).

Place integration has been used in this thesis to understand challenges and problematic situations that people with dementia experience when doing everyday activities in public space, and how they meet these situations.

Space and place

Two important concepts in this thesis are space and place. The concept of public space is regarded here as a space that all citizens have access to and comprises all space outside the person's home. This could include outdoor environments such as streets and parks (Tibbalds, 1992) and indoor environments such as libraries and museums (Carmona, Heath, Oc, & Tiesdell, 2003) and shopping centres, but not private homes and buildings. In Sweden public space has been described as “[the part of the built environment that is accessible by the public, for example streets, passages, galleries, squares, and parks] (*National Encyclopaedia*. 20130526) (translated by author).

Within public space there are specific places that comprise a unique meaning for the person because of the person's transactional relationship and of his cultural and social character's association with the place (Cutchin, Steven, Owen, & Chang, 2003). For example a certain shop or park could hold specific meanings for the person because of his or her cultural and social character. There are places in public space where people may feel a sense of belonging, of being welcomed and safe whilst other places may be experienced as hostile and dangerous. Over the life course there are ongoing processes of making spaces into places and these processes are complex. They involve creating neutral geographical spaces into places that have a personal meaning for that specific person. This process provides the person with a sense of security and familiarity, and of control, identity and comfort (Rowles & Bernard, 2013).

In summary, the difference between the concepts of place and space are that the concept of place emphasizes the meaning of people's experiences much more than does the concept of space (Cutchin et al., 2003).

Accessibility and usability

The concept of accessibility is widely used in different disciplines. It often has different meanings and is usually used without specific definitions (Iwarsson & Ståhl, 2003). In general language, accessibility means being at hand, attainable, approachable, available, close, convenient and within reach (*Oxford Dictionary and Thesaurus*, 2010). In science, one definition of accessibility is the encounter between the design and demands of the physical space and the person's capacity (Iwarsson & Ståhl, 2003; Letts, Rigby, & Stewart, 2003). Accessibility is mainly based on norms and standards and is objective in its nature (Iwarsson & Ståhl, 2003). Lawton's ecological model of

aging is often associated with accessibility, where accessibility is viewed as being dependent on the relationship between individual competence and environmental press, but with the focus on separate entities (Lawton, 1986; Lawton & Nahemow, 1973). In the docility hypotheses it is proposed that persons with lower competencies are more vulnerable to environmental press while people with higher competencies can manage greater environmental press. A balance may be achieved by changing the environmental press or the person's competence or both (Lawton & Simon, 1968). Most accessibility research has to date been based on Lawton's and Nahemow's ecological model of aging (1973) (Fänge, Iwarsson, & Persson, 2002; Fänge & Iwarsson, 2005; Jensen, et al., 2002).

Iwarsson and Ståhl (2003) challenged the current terminology of accessibility when they suggested that the personal and environmental components must be analysed together. Another important aspect is that they suggest that the activity component should be introduced.

In this thesis the concept of accessibility in public space is viewed from a transactional perspective. In this view accessibility is influenced by the ongoing interplay between environment and person, based on John Dewey's philosophy (Cutchin, 2004). The public space is not just a physical place; it also embraces cultural, social and political aspects and includes temporal and spatial dimensions. Those dimensions are internalized by the person with dementia, who interacts with the public space and creates inseparable connections between them (Cutchin, 2004; Dickie et al., 2006). Accessibility has been used in a more complex way than suggested by Lawton. In other words the focus has not been limited to environmental press and individual competence (Lawton, 1986) but also embraces relationships between the persons and the environments (Cutchin, 2004; Dickie et al., 2006).

A concept that is closely associated with accessibility is usability. Accessibility is also seen as a precondition for usability and is mainly subjective in its nature (Iwarsson & Ståhl, 2003). The Swedish Building and Planning Legislation emphasizes that usability and accessibility may be used jointly. It requires that all buildings for work, housing or other premises open to the public must be usable and accessible for persons with restricted sense of mobility and locality (Didón, Magnusson, Millgård, & Molander, 1987). In the public space there are many products that the inhabitants have to use in order to experience accessibility. One of the definitions related to products is the International Organization for Standardization (International Organization for

Standardization, ISO, 1998), which has defined usability as “*The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use*”. In this thesis the concept of usability has been used to capture the informant’s perception of usability, meaning that a person can be in and using an environment, including different products such as cash machines, and move around in public space on equal terms with other inhabitants.

Everyday activities in public space - challenges and benefits

In the following, challenges and benefits of doing everyday activities in public space will be described. Dementia will first be introduced as it is conceived based on a traditional medical perspective and related to everyday life.

Thereafter aspects of doing everyday activities with the specific focus on grocery shopping and being a pedestrian will be elaborated. Way finding and how to manage everyday activities will also be addressed, with older people and people with dementia in particular in focus. Lastly, design principles for dementia-friendly environments will be presented.

Dementia

Dementia is a generic term that describes progressive and chronic dysfunction of subcortical and cortical function that will result in cognitive and functional decline (Ritchie & Lovestone, 2002; APA, 2000). Alzheimer’s disease (AD) is the most common diagnosis in dementia in the elderly population (Cummings & Cole, 2002). The symptoms of dementia include decline of memory and other cognitive domains, for example apraxia, aphasia, disturbance in executive functioning and agnosia (APA, 2000; McKhann et al., 1984). It is common that complex instrumental activities of daily living (IADL)s such as shopping and managing finances are affected long before the dementia is diagnosed (Desai, Grossberg, & Sheth, 2004). Activities of daily living (ADL) such as eating and dressing are influenced in a later stage of dementia (Liu et al., 2007).

In this thesis people with mild to moderate dementia as determined by the well-known Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) have been included as informants. There is a variation between different studies regarding the cut-off scores for the stages of dementia. Jönsson and Wimo (2009) suggested that

mild dementia is indicated by MMSE scores above 20, moderate dementia between 10 and 19 and severe dementia less than 10. In mild dementia the person has moderate memory loss that influences everyday activities. The person may have difficulties with geographic disorientation and with time relationships. In community affairs, the person may be unable to function independently, but may still be engaged in some. In severe dementia only fragments of memory remain. The person may be oriented to persons, but is unable to solve problems, unable to make judgments and needs much help to manage personal care (Hughes, Berg, Danziger, Coben, & Martin, 1982). However, at present people tend to live longer in ordinary housing regardless of their stages of dementia (*National Guidelines for Care in Cases of Dementia*, 2010).

Having laid out stages of mild to moderate dementia, the focus will shift to the occupational perspective of doing everyday activities in public space in the aging population in general, and of people with dementia in particular.

Everyday activities in public space

Having access to and being engaged in everyday activities in public space has been found to be important and to influence older people's health in different ways (Law, 2002). For example, life satisfaction could be positively influenced if the public space is safe and pleasant (Sugiyama, Thompson, & Alves, 2009), and both quality and quantity of outdoor activities are relevant to older people's health (Oswald, Jopp, Rott, & Wahl, 2011; Sugiyama & Ward Thompson, 2007). Moreover, social engagement and physical engagement could promote vitality and cognitive health (Cedervall & Åberg, 2010; Yevchak, Loeb, & Fick, 2008). The quality of neighbourhood environments has a strong association with good functioning and good health, for example closeness to shops, trust of people in the neighbourhood and good quality of facilities (Bowling, Barber, Morris, & Ebrahim, 2006). Another aspect important to health is that sunlight helps to regulate the sleep cycle (Brawley, 2001).

Studies have found that people with dementia also value being able to stay active and continue with their everyday lives as they did before their diagnoses (Egan, Hobson, & Fearing, 2006; von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012; Öhman & Nygård, 2005), for example taking walks, doing grocery shopping, and visiting friends in public space (Duggan, Blackman, Martyr, & Van Schaik, 2008; Phinney, Chaudhury, & O'Connor, 2007). The most common destination identified in

public space is the local shop, and thereafter the post office, going nowhere in particular or visiting friends (Burton, 2006; Mitchell & Burton, 2006).

The benefits of being involved in activities creates feelings of enjoyment and pleasure, a sense of belonging and connection and a retained sense of personal identity and autonomy for the persons with dementia (Phinney et al., 2007). By doing activities independently they may feel autonomy and freedom. In one study, other important benefits of doing activities in public space were that informants felt a sense of worth and dignity, mental health and possibilities for social interactions (Burton, 2006). But findings from another study showed that they could also experience feelings such as anxiety, confusion, disorientation, boredom as well as feelings of comfort and happiness when doing everyday activities in public space (Mitchell & Burton, 2006).

However, older people encounter challenges when doing activities in public space. Women are more likely to experience fear of moving outdoors. Different aspects correlated with their fear of moving outside are slow walking speed, musculoskeletal diseases, hills in the nearby environment, poor street conditions and noisy traffic (Rantakokko, Iwarsson, Mänty, Leinonen, & Rantanen, 2012). Such challenges in accessing public space are likely to be the same for people with dementia as for older adults in general, but little knowledge exists regarding particular challenges that people with dementia may experience when doing everyday activities in public space. The current knowledge is that people with dementia may be disoriented, have difficulties navigating and interpreting the environment. In addition, the environment may be experienced as distressing and threatening (Blackman et al., 2003).

To sum up, the benefits of having access to everyday activities in public space for people with dementia are likely to influence their health in a positive way, as they do for older people in general. Many different benefits and challenges of doing everyday activities in public space have been described for the aging population, and some findings were related to people with dementia. However there is a lack of knowledge regarding how people with dementia experience access to specific activities in public space.

Being a grocery shopper

One important activity performed by older adults as well as by people with dementia in public space is doing grocery shopping (Duggan et al., 2008), but the knowledge is sparse about how people with dementia experience their grocery shopping and how they manage problems. In the following an overview will be given of the benefits and challenges of doing grocery shopping for older people in general, and for people with dementia in particular.

Doing grocery shopping on one's own is important for older adults and may be related to a higher level of life satisfaction and independent living (Smith, 1991). Another benefit described is the possibility of obtaining social contact and physical exercise when doing grocery shopping. The local shop has also been identified as important for independent shopping (Sidenvall, Nydahl, & Fjellström, 2001). In contrast, another study showed that older people preferred to visit department stores (Valdemarsson, Jernryd, & Iwarsson, 2005), and yet other studies indicate that the shopping centre was of great importance. It may be a place where they could "hang out", doing nothing more than walking around, observing or talking (White, 2007). But doing grocery shopping could be experienced as a challenge for the customer in general. Challenges described in studies are crowding (Eroglu, Machleit, & Barr, 2005; Machleit, Kellaris, & Eroglu, 1994; Pan & Siemens, 2011), products being hard to find, difficulties in finding what the person needs, complicated modes of payment and items in store having been changed. Challenges related to loud music and people moving slowly have also been reported in one study (d'Astous, 2000). In another study, older people described that they experienced negative factors in the shop such as poor check-out stations, unpleasant staff, lack of assistance in the shop, feeling unsafe when shopping, inaccessible shelves and poor labelling (Hare, 2001). Other reported problems are changes in store layout (Meneely, Burns, & Strugnell, 2008). Supermarket managers have an important role in developing an accessible and usable grocery shop for older customers. Pettigrew proposed that managers should develop strategies to ensure that staff members are trained to enable them to engage in positive interactions with older customers (Pettigrew, 2005).

Grocery shopping is an activity that can be difficult to perform for people with dementia (Liu et al., 2007), and grocery shopping is also an important part of mealtime activities (Johansson, Christensson, & Sidenvall, 2011). For example in one study

80.7% of the included women were unable to do grocery shopping (Lechowski et al., 2008), but in contrast another study indicated that ten out of fifteen informants did their grocery shopping by themselves. Studies suggest that people with dementia value doing grocery shopping (Duggan et al., 2008; Johansson, 2013; Mitchell & Burton, 2006). However, grocery shopping concerns so much more than the actual shopping. The person has to get to the grocery shop and this commonly involves walking, interaction with traffic and finding one's way in public space.

Way finding

Way finding is a process that people in general go through in everyday activities, for example in public space. Experiencing way-finding difficulties may cause problems related to decreased safety, discomfort, stress and loss of time for people in general (Passini, Rainville, Marchand, & Joannette, 1998).

Challenges in find one's way in the world are problematic for people with dementia, and disorientation appears early in AD (Duggan et al., 2008; Liu, Gauthier, & Gauthier, 1991; Pai & Jacobs, 2004). Disorientation refers to difficulty in navigating through, orienting to and feeling familiar with the surroundings (Cherrier, Mendez, & Perryman, 2001; Henderson, Mack, & Williams, 1989). In the early stage of dementia, getting lost when travelling in unfamiliar places is common. But during the later stages of dementia, people may get lost even in familiar places (Rainville, Passini, & Marchand, 2001; Sheehan, Burton, & Mitchell, 2006). Reasons for experiencing disorientation may be reduced ability to remember streets, places and names and alternative directions and routes (Burton, 2006), and the spatial disorientation will influence the way-finding ability (Blackman et al., 2003).

To sum up, way-finding problems for people with dementia in public space are well-known. But finding one's way in public space also means that the person has to relate to many different situations that occur at the same time, for example in traffic. There is a lack of knowledge regarding people with dementia as pedestrians doing everyday activities in relation to everything that goes on in public space.

Being a pedestrian

A major problem in public space is traffic incidents involving older pedestrians (Hamed, 2001) and their unsafe road-crossing behaviour (Sullman et al., 2011). Challenges described by older people as pedestrians are that there is a lack of separation of cyclists and pedestrians on sidewalks (Ståhl, Carlsson, Hovbrandt, & Iwarsson, 2008; Wennberg, Ståhl, & Hydén, 2009), that there is a lack of wider sidewalks and of maintenance of sidewalks (Ståhl et al., 2008), and that there is a lack of traffic lights and crossings (Valdemarsson et al., 2005). Older people also found the lack of ice prevention to be a challenging matter (Wennberg et al., 2009). Other challenges described are that older people have difficulties doing multitasking, such as simultaneously talking on the cell phone and crossing a street (Neider et al., 2011), and they tend to select insufficiently large gaps between cars when crossing a road (Oxley, Ihlen, Fildes, Charlton, & Day, 2005). Vehicle speeds were found to be a very important challenge for being able to cross a road in a safe way (Lobjois & Cavallo, 2009). The reasons for these challenges could be connected to the fact that older people do not walk as fast as they did before, and therefore they can endanger themselves by underestimating the time that it will take them to cross the road (Zivotofsky, Eldror, Mandel, & Rosenbloom, 2012). Hence speed reduction through road narrowing and speed ramps is important (Dommes, Cavallo, Vienne, & Aillerie, 2012).

To date there is little knowledge about how people with dementia experience different traffic situations as pedestrians. It has been found that people who had died in traffic incidents had dementia to a greater extent in comparison to a control group (Gorrie, Brown, & Waite, 2008). Research also suggests that cognitive decline may be a factor in fatal traffic accidents for older pedestrians with AD (Gorrie, Rodriguez, Sachdev, Duflou, & Waite, 2006). This is important to highlight, as the mode of transportation most used by older people is walking, followed by car driving (Risser, Haindl, & Ståhl, 2010). However, there is research concerning driving and dementia (Brown & Ott, 2004; Carr, Barco, Wallendorf, Snellgrove, & Ott, 2011; Hunt, Brown, & Gilman, 2010; Lincoln, Taylor, Bouman, & Radford, 2009), but to date there is little knowledge regarding how people with dementia experience and manage being pedestrians in public space.

The design of streets was identified as a challenge for pedestrians with dementia in one study, as it could cause confusion when streets are not clearly demarcated from pavements and in this case they could be harder to distinguish (Van Schaik, Martyr,

Blackman, & Robinson, 2008). Another challenge in public space experienced by people with dementia was found to be unattractive street layouts (Van Schaik et al., 2008). Many people with dementia experience a fear of being run over by cyclists or vehicles. According to Burton (2006), people with dementia tend not to trust drivers to stop, and they prefer light-controlled pedestrian crossings. The participants in Burton's study also experienced that non-controlled traffic islands were useful, as they enabled them to cross the road in two stages.

Ways of managing everyday activities in dementia

It is known that people with dementia engage in everyday activities that they experience as meaningful (Öhman & Nygård, 2005), but their participation in everyday activities is challenged (Svanström & Dahlberg, 2004) and they have to respond to and manage problems (Nygård & Öhman, 2002). People with dementia do not submit to the disease passively, and they use strategies to deal with challenges (de Boer et al., 2007). The strategies used by people with dementia can work or fail, despite their best efforts (Preston, Marshall, & Bucks, 2007). The development of strategies is important in minimizing excess disability and maximizing well-being (Clare, 2002), in retaining mastery and a sense of control over everyday life (Nygård, 2004), and in maintaining lifestyle (Roach, Keady, Bee, & Hope, 2008). In the literature a variety of strategies used by people with dementia to manage everyday activities are described, but few of those studied have addressed how they manage problems when doing everyday activities in public space. In the following, different ways of managing common everyday activities will be described.

One way of managing everyday activities is to modify the way the activity is performed or stop doing activities (Lee et al., 2006; Öhman et al., 2008). Another way is to repeatedly check what one just has done (Nygård & Öhman, 2002; Öhman et al., 2008). One study showed that being extra cautious, being alert and present are other strategies for managing everyday activities (Nygård & Öhman, 2002). The person with dementia can also stop and think when encountering a problem (Nygård & Öhman, 2002; Pearce, Clare, & Pistrang, 2002). Other strategies are described in various studies; they include doing one thing at a time (Nygård & Öhman, 2002; Preston et al., 2007), talking to oneself (Nygård, 2004), and getting help from others (Clare, 2002; Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008; Phinney, 2006; Preston et al.,

2007). Getting help from others could include being accompanied by friends or relatives, a situation which reduced demands and guided the person with dementia when doing activities (Phinney, 2006). To compensate for memory decline, written reminders such as notes and memos were found in several studies to be important strategies (Joosten-Weyn Banningh et al., 2008; Marquardt et al., 2011; Nygård & Starkhammar, 2003; Nygård & Öhman, 2002; Preston et al., 2007; Öhman et al., 2008). Strategies for managing everyday activities were commonly based on routines and habits (Cedervall, Kilander, & Åberg, 2012; Johansson et al., 2011; Johansson, 2001; Nygård & Öhman, 2002). Clare (2002) proposes that it is of great value and also a challenge to help people with dementia to find strategies to strengthen their sense of self and maintain hope. According to Nygård (2004) it is also important to acknowledge the response strategies used by people with dementia.

Managing way finding

One common strategy used by people with dementia to facilitate way finding was identified in several studies to be the use of landmarks and signs (Delpolyi, Rankin, Mucke, Miller, & Gorno-Tempini, 2007; Passini, Pigot, Rainville, & Tetreault, 2000; Sheehan et al., 2006). Different landmarks could be buildings and places of personal significance, places of activity such as parks, distinctive structures such as public art and water towers and historic buildings (Mitchell & Burton, 2006). But using the landmarks had to be associated with the destination, otherwise the landmark could be experienced as a barrier (Van Schaik et al., 2008). A study has pointed out that signs must be developed for people with dementia (Sheehan et al., 2006), displaying the message in a clear way and using numbers and words (Blackman, Van Schaik, & Martyr, 2007).

Another strategy for finding one's way in public space is the use of maps, but people with dementia have difficulties in using this technique (Blackman et al., 2007; Delpolyi et al., 2007; Van Schaik et al., 2008). It has also been found that people with dementia may increase their ability to find their way after interventions (McGilton, Rivera, & Dawson, 2003).

To date the research has mainly focused on way finding and strategies used by people with dementia, but being in public space is not just about way finding. The people with dementia have goals in public space, such as taking a walk or doing grocery shopping,

and in this way the activity component is added to finding the way, making it more complex.

In summary, various different strategies have been identified in research, and the strategies used are mainly initiated by people with dementia but linked to activities performed in the home. To date some knowledge exists about how people with dementia manage way finding in public space. But the knowledge is very sparse regarding what kind of problematic situations people with dementia might experience when doing activities in public space, and how they would meet these situations.

Design principles for people with dementia

To date the literature and research on accessibility for people with dementia have mainly focused their attention on architectural design and planning of care facilities in order to create supportive living environments. The design has been viewed as a therapeutic resource and a promotion of functionality and well-being among people with dementia (Day, Carreon, & Stump, 2000). The design principles emphasize sensory stimulation, non-institutional character, safety and lighting. Furthermore, the design of specific rooms has also been in focus, for example how to design dining rooms, residents' rooms, kitchens and bathrooms (Brawley, 2001; Day et al., 2000). In an overview, the recommended principles of designing accessible and usable living environments for people with dementia were characterized as being clear and structured, stable and familiar, providing safety and security, and reducing unnecessary stimulation (Brawley, 2001; van Hoof, Kort, van Waarde, & Blom, 2010).

To date, research has highlighted that people with dementia should have access to the outdoor space. However design principles regarding outdoor space have mainly concerned how to design gardens at care facilities such as healing and restorative gardens and wandering parks (Brawley, 2007; Chapman, Hazen, & Noell-Waggoner, 2007; Schwarz & Rodiek, 2007), without including the general public space. But recently the importance of design principles regarding public space has been emphasized, and it has been suggested to make public streets accessible and usable regarding navigation (Mitchell, Burton, Blackman, Jenks, & Williams, 2003). Different aspects are described, such as *familiarity*, referring to streets being recognizable and easily understood. Another aspect is *legibility*, referring to the extent to which street signs help older people to identify which way they need to go and understand where

they are. *Comfort* has to do with the extent to which a street enables the person to visit places without mental and physical discomposure and to enjoy being in the public space. Furthermore, *accessibility* of streets enables people to enter, reach and walk around places they wish and need to visit. *Safety* is another aspect of designing streets to enable people to enjoy, use and perform activities in public space without fear of falling, being run over or tripping. And lastly, *distinctiveness* focuses on how the street can give a clear image of where the person with dementia is and where the streets lead (Burton, 2006).

Davies (2009) proposes that today the focus should be on the experiences of everyday life of people with dementia, and their experiences should frame the process of creating appropriate environments. A dementia-friendly environment has been defined as “A *cohesive system of support that recognizes the experience of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way*” (Davis, Byers, Nay, & Koch, 2009, p187). This was also highlighted by Blackman et al. (2003), who stated that if we want to understand how public space could be made more accessible for people with dementia, they have to be involved in research as active informants.

Summary of the introduction

The literature review has shown that community-dwelling people with mild to moderate stage dementia value being able to continue with their life and everyday activities as before their diagnosis. Many of their activities are done in public space. Accessibility in public space has mainly been viewed from a physical point of view but lately studies have directed attention to people with dementia as users of public space and the kind of problems they might experience. However, the research in this field is still sparse.

People with dementia use many different strategies to meet problems in their everyday lives, particularly within their home environments. Nonetheless, there has been little research on how problems in public space are experienced and on how they meet problematic situations with different actions. More research is needed focusing on how people with dementia experience access to everyday activities and how they meet problematic situations in public space. A transactional perspective can be used to understand the relationship between the person and the environment and to challenge

the common dualistic view based on environmental demands and capacities of the person.

RESEARCH AIMS

The general aim of this thesis is to increase knowledge about problematic situations in public space as experienced by community-dwelling people with dementia, and about how they meet these situations when doing everyday activities. The aim also includes increasing knowledge about transactions between people with dementia and public space.

The specific research aims in the thesis were to:

- Illuminate experiences of accessibility in public space in people with AD, with particular focus on places, situations and activities that they found important for daily life (Study I).
- Discover and describe problematic situations and critical incidents that took place when people with AD performed grocery shopping, and how these incidents were met by them (Study II).
- Identify characteristics of the space of a grocery shop and how these characteristics meet the prerequisites of people with dementia (Study III).
- Identify problematic situations at zebra crossings, and how people with dementia would understand, interpret, and act in these problematic situations, based on their previous experiences, and linked to the film sequences (Study IV).

METHODS

Design

In this thesis new knowledge was developed about accessibility in public space for people with dementia by using a qualitative inductive design. The same methodological approach, grounded theory, was used in the four studies. Access to everyday activities in public space is a newly developed research area and therefore a grounded theory approach was seen as appropriate, as it is common to use this approach when there is a lack of knowledge in a research area (Glaser & Strauss, 1967). Furthermore, a grounded theory approach was chosen because the focus was on strategies, interactions and consequences of having access to everyday activities (Corbin & Strauss, 1998; Glaser & Strauss, 1967).

The four studies were built on each other, that is, findings from the first study showed that public space was important for doing activities, and one important activity done by people with dementia was grocery shopping. Hence, in the second study the interest was in getting deeper knowledge about critical incidents and how the informants met them when doing grocery shopping. From the results of the first two studies the space of a grocery shop came to the fore as important for the informants' experiences of accessibility. Therefore the aim of the third study was to identify the characteristics of the space of a grocery shop that influenced accessibility, as well as how these characteristics meet the prerequisites of people with dementia. Finally, the focus in the fourth study was on identifying problematic situations in using zebra crossings. Identification was made from photo documentations and from the perspective of people with dementia and how they understand, interpret and act in these situations. This issue was highlighted in the three previous studies when activities in public space included interaction with different traffic situations.

Grounded Theory

Grounded theory approaches have been used in all four studies (Corbin & Strauss, 1998; Glaser & Strauss, 1967). This approach is common in occupational therapy and occupational science research (Nayar, 2012; Stanley & Cheek, 2003) as well as in studies including people with dementia (Rosenberg & Nygård, 2012; Starkhammar & Nygård, 2008). An overview of the four studies in the thesis is presented in Table 1.

Table 1. Overview of the four studies included in the thesis.

	Study I	Study II	Study III	Study IV
Focus	Illuminating experiences of accessibility in public space with the focus on places, situations and activities important for daily life	Exploring different critical incidents in grocery shopping and how informants met them	Identifying characteristics that influence accessibility in the space of a grocery shop and how these characteristics met the informants' prerequisites	Identifying problematic situations in using zebra crossings from two different perspectives. Identifying how informants understand, act and interpret problematic traffic situations.
Number of informants	n=7	n=6	n=6	n=6
Design	Explorative qualitative study	Explorative qualitative study	Explorative qualitative study	Explorative qualitative study
Method of data collection	In-depth interviews	In-depth interviews and observations	Visual methodologies: photographs and focus group interviews with photo elicitation	Visual methodologies: film sequences and focus group interviews with film elicitation. Individual in-depth interviews.
	13 interviews	12 interviews 8 observations	3 photo sessions (373 photos) 2 focus group interviews	22 recordings (1hr 32 mins) 1 focus group interview 3 individual interviews 1 focus group interview
Analysis	Grounded theory approach	Grounded theory approach	Grounded theory approach.	Grounded theory approach.

In this thesis inspiration from Grounded Theory presented by Corbin and Strauss (1998, 2008) was mainly used, but it has to be pointed out that inspirations from others have also been adopted, for example from Glaser and Strauss (1967) and Charmaz (2006). One of the reasons for adopting Strauss and Corbin's way of conducting grounded theory was their theoretical framework of pragmatism and symbolic interactionism (Corbin & Strauss, 1998), as this was in line with the theoretical framework of the thesis.

Informants

The ambition of the four studies has been to illuminate how people with dementia experience accessibility when doing activities in public space. Therefore people with dementia in mild to moderate stages, living in ordinary housing and doing to some extent activities in public space by themselves were included as informants. An overview of the informants' characteristics is presented in Table 2.

Table 2. Demographic characteristics of the informants in the thesis.

	Study I	Study II	Study III	Study IV
Number of informants in the study sample	n= 7	n= 6	n= 6	n=6
Sex Female/Male	5/2	4/2	6/0	3/3
Living condition Cohabiting/single	3/4	3/3	1/5	3/3
Location of home City centre/suburb	3/4	2/4	1/5	3/3
Age, years Mean, (range)	68.8 (64-80)	69.7 (63-80)	63.6 (57-70)	74.8 (66-86)
Diagnosis	7 AD	6 AD	5 AD, 1 FTD	6 AD

AD= Alzheimer's' disease

FTD= Frontotemporal dementia

Studies I and II

In Study I, the seven informants were recruited from a dementia investigation unit and a dementia association. The inclusion criteria were an age of 55 or older, being able to share their experiences of situations outside their homes, being able to reflect and being diagnosed with mild Alzheimer-type dementia based on NINCDS-ARDA (McKhann et al., 1984). The criteria for AD require impairment in at least two cognitive domains

such as apraxia, aphasia, disturbance in executive functioning and agnosia and memory deficits must be progressive (McKhann et al., 1984). In Studies I and II the number of years since diagnosis varied between one year and six years.

In Study II, six of the informants from Study I were included.

The informants' characteristics are described in Table 2.

Study III

In Study III, six informants in total were recruited from an Alzheimer Association Centre. The inclusion criteria were that the informants should do some grocery shopping and be diagnosed with dementia. The number of years since diagnosis varied between one and four years. The informants' characteristics are described in Table 2.

Study IV

In Study IV, six informants in total were recruited. Three of the informants were recruited from a dementia association and three from an Alzheimer Association Centre. The inclusion criteria were that the informants should be diagnosed with dementia and do activities in public space that involved being a pedestrian. The number of years since diagnosis varied between one and nine years. The informants' characteristics are described in Table 2.

Data collection

In grounded theory as in other qualitative research methods there are many alternative ways of collecting data. It is common to use observations, interviews, documents, photographs, videos, diaries, newspapers, memoirs, historical documents and biographies. These methods can be used in combination or by themselves (Corbin & Strauss, 2008).

The data collection in Studies I and II was conducted with in-depths interviews. In Study II observations were also performed when informants did grocery shopping. Studies III and IV were conducted with photo documentation (photographs in Study III and film sequences in Study IV) and focus group interviews in combination with photo elicitation (Studies III and IV). In the following these data collection methods and the motives for the choices will be described.

Individual interviews

In Studies I, II and IV individual interviews were used as the data collection method. The purpose of interviewing was to obtain knowledge about people with dementias' perspectives (Patton, 2002) of access to everyday activities in public space, with the particular focus on activities, situations and places. The data collection in Studies I and II was performed between June 2008 and September 2009 in the Stockholm area. The interviews took place in the informants' homes and lasted from 40 minutes to 1 hour and 40 minutes. All informants were interviewed twice except for one person, making a total of 13 interviews. All interviews were recorded digitally and transcribed verbatim. The interview guide comprised open-ended questions (Kvale, 1996) and captured, for example, what kind of daily activities in public space the informants were engaged in and what problematic situations they experienced. An example of a question asked was: *What do you do outside your home?* In the second interviews interesting tracks and significant statements from the first interviews were elaborated. In the interviews probes were used to increase depth and richness of responses (Patton, 2002). In Study II, data regarding critical incidents in grocery shopping and how the informants tried to overcome these were explored in the interviews from Study I. Hence the same interviews were used in Studies I and II. In this case questions were posed to the already existing data. Examples of questions included: *Where did the critical incidents happen? Why were the incidents experienced as critical for the informants?* and *How did they meet the critical incidents?* In Study IV individual interviews were performed with three informants after the first focus group interview, when aspects of being a pedestrian had to be further elaborated upon by asking specific questions such as: *Why do you avoid crowding?* The individual interviews in Study IV were performed in the informants' homes and on a day of their choice. The interviews lasted from 35 to 50 minutes each.

Critical Incidents Technique

To investigate problematic situations and critical incidents in grocery shopping (Study II), inspiration from the Critical Incidents Technique (CIT) (Flanagan, 1954) was used. CIT consists of different procedures for collecting observations of human behaviour to facilitate solving practical problems (Flanagan, 1954). CIT has been used in studies to solve practical problems such as use of urban transportation (Jensen, et al., 2002) and consumer shopping (Arnold, Reynolds, Ponder, & Lueg, 2005). The definition of

critical incidents by Flanagan is “*any observable human activity that is sufficiently complete in itself to permit inferences and predications to be made about the person performing the act*” (Flanagan, 1954, p. 327).

In Study II problematic situations were considered to be challenging phases of grocery shopping. The problematic situations were also viewed as comprising different critical incidents. These incidents were defined as any potentially hazardous aspect of a problematic situation that required some actions by the informants (Brorsson, Öhman, Cutchin, & Nygård, 2013).

Observations

The data collection in Study II included participant observations in addition to interviews. Conducting participant observations is suitable for capturing situations when they actually occur in the natural settings (Burgess, 1984). In this study the aim was to capture problematic situations and critical incidents and observe how the informants reasoned to meet these situations when they actually occurred while doing grocery shopping. What kind of critical incidents or problematic situations were to be observed were not predicted in advance. The observations were performed during 2009 and 2010 in the Stockholm area. In total eight observations were done, with six informants. The time range of the observations varied between 33 and 57 minutes. All of the observations started in the informants’ homes, as the activity of grocery shopping was regarded as beginning there. Observations were conducted at different seasons of the year to capture different problematic situations and critical incidents.

During the participant observation (Burgess, 1984) one researcher walked behind the informant and observed what kind of critical incidents happened and how the informant met them with different kinds of actions. That researcher also observed what was happening in the public space, for example if the traffic was heavy, if there were crowds of people or objects on the sidewalk. In addition, another researcher walked beside the informant and performed an interview while the informant was doing grocery shopping. The focus was on identifying critical incidents when they actually occurred and how the informants reasoned about them. After the observations, separate field notes were made by the two researchers. To capture the conversations and noise in the background the observations were recorded digitally and transcribed verbatim. The

researcher walking behind also did digital recordings with verbal observation, for example if there was a high kerb or if the informant stumbled.

Visual methodologies

In Studies III and IV visual methodologies were used in the data collection in addition to focus group interviews, starting with photo documentation comprising photographs (Study III) and film sequences (Study IV). In photo documentation the researcher takes the photos and film sequences (Rose, 2007), in comparison to photo voice where the informants take the photos (Wang & Burris, 1997).

The photo sessions and film recordings were guided by shooting scripts. Shooting scripts are described as research questions that may be asked via photographs or film sequences (Suchar, 1997). This meant that different questions were posed, for example in Study III the question *How is the layout in the grocery shop?* and in Study IV, *What is happening at a zebra crossing without traffic lights?* These questions were investigated via photos (Study III) and via film sequences (Study IV).

In the first step of Study III, photo documentation (Rose, 2007) was used and researcher AB took photographs in a smaller grocery shop in a housing area. The shooting was done on three different occasions between March 2011 and August 2011. Each photo session was done in the morning before opening hour and lasted about 45 minutes. In total 273 photos were taken.

In Study IV film sequences were made by researcher AB (Rose, 2007) and were guided by shooting scripts at different zebra crossings in a medium-sized and a big city.

Twenty-two different film sequences were done on nine different occasions between March 2011 and February 2012. The total recordings were 1 hr 32 mins. The filmmaking was performed at different seasons and times of the days. The filmmaking started at one zebra crossing. Thereafter the film sequences were looked through and new questions were added to the shooting script such as *What is happening at a zebra crossing with a traffic island?* The filmmaking was continued until no new aspects were seen in the different film sequences.

Field notes were taken after each photo and film recording session, noting date, time and description of the place. After each session the photographs and film sequences were analysed visually by the co-authors and this resulted in new questions being added to the shooting scripts to be used in the next photo session and film recording, for

example *How can the understanding of check-out stations be expanded if the photo is made from a different angle?*

Focus group interviews

In the second step of data collection in Studies III and IV, focus group interviews in combination with photo elicitations (Study III) and film sequences (Study IV) were undertaken. In photo elicitations, photographs or film sequences are inserted into the research interview (Harper, 2002) as stimulus material to enhance the discussion using triggers (Barbour, 2005). Focus group interviews are useful for discovering new information and gaining information from the informants' perspective, for example experiences, attitudes and feelings about a specific topic within the group (Krueger & Casey, 2009; Litosseliti, 2003). The group interaction is important to produce data and consensus in the discussion is not the goal (Morgan, 1997).

In Study III, two focus groups were performed in March 2012, lasting between 90 and 130 minutes. Each focus group consisted of three informants and six informants were included in total. The focus groups were led by one moderator, AB, and one assisting observer, SL. The topic of discussion was the space of a grocery shop and the characteristics that may influence accessibility in grocery shopping. To enhance and stimulate the discussion material in the form of five photographs in colour, i.e. photo elicitations, were shown on a computer screen. The five photos were carefully chosen in order to create a feeling of taking a walk through a grocery shop from the entrance to the check-out stations. The photos captured different situations and places in the grocery shop, for example the entrance and the vegetable stands. The photos were shown on the computer screen and each informant received the same A4-sized photograph. When changing the photo on the computer screen the moderator handed out new photos and the old ones were collected. The reason for collecting the old photos was that the informants should look at the same photo and that the photos should not be mixed up.

In Study IV, focus group interviews in combination with photo elicitations (Harper, 2002) were used, meaning that five different film sequences from the analysis of photo documentation were used in order to capture the complexity variations of zebra crossings. The film sequences were shown on a wall screen as triggers in the focus group interviews, with the time ranging from 40 seconds to 1 minute and 55 seconds.

The reason for showing the film sequences on a wall screen instead of on the computer screen was that everybody would be able to see. The topic of discussion was how it was to be a pedestrian at a crossing, what kind of problematic situations the informants experienced and how they met these situations. Questions raised by the moderator were for example *What did you observe on this film sequences?* and *If you were about to cross the street that you observed on the film, can you describe your thoughts?*

The same moderator and assisting observer led the focus group discussions in Studies III and IV. The informants were encouraged to share their thoughts and experiences and it was emphasized that nothing was wrong or right (Krueger & Casey, 2009). The intention was not to unnecessarily disrupt the informants' discussion; the moderator intervened only when informants were silent or when issues could be elaborated further. The context of the focus groups was a familiar setting for all the informants; they took place at the Alzheimer Association or the Dementia Association. The use of familiar contexts was motivated by the aim to facilitate the informants' ability to find their way to the location, to create a comfortable atmosphere and enhance participation in the study. The room was free from disruption and to create a pleasant atmosphere, informants were offered fruit, water and coffee throughout the discussion (Barbour, 2005; Krueger & Casey, 2009). All focus group interviews in Studies III and IV were recorded digitally and transcribed verbatim.

Data analyses

All the studies in the thesis were analysed using the principles of comparative analysis based on grounded theory (Corbin & Strauss, 1998; Glaser & Strauss, 1967).

Visual data in Studies III and IV were analysed by the same principles of comparative analysis but based on Suchar's method (1997), which also originates from the principles of grounded theory (Glaser & Strauss, 1967).

Comparative analysis based on Grounded Theory

Data analysis started immediately after the first data collection, following the principles of grounded theory (Corbin & Strauss, 1998), meaning that data collection and analysis were done at the same time. Data analysis started with listening several times to the digital recordings from the individual interviews, observations and focus group

interviews to identify new aspects to be elaborated on in the following data collection. After this digital recordings were transcribed verbatim and read several times.

Theoretical sampling means to refine and elaborate categories in order to fill gaps, and the sampling continues until the gaps within a category are fulfilled (Charmaz, 2006). In Studies I, II and IV the coding process started when all data were transcribed, but in Study III the coding process started immediately after the digital recordings were transcribed verbatim and thereafter the second focus group was made. A complete theoretical sampling has not been done in this thesis, as the coding process did not start right after the first data collection.

The first step of coding was the open coding. In the open coding data was broken apart, all data were coded line by line and the codes were given names close to the data (Corbin & Strauss, 1998) that also described an action (Charmaz, 2006).

Codes were constantly compared to each other and codes that related to each other created different categories. In the next step of data analysis, axial coding was used to discover how the categories were related to each other. This process led to the core category (Corbin & Strauss, 1998). The core category was central and linked various pieces of data together (Corbin & Strauss, 2008).

In Study I, each category also presented its properties, describing the characteristics of the categories. Furthermore each of the properties was also described with dimensions, covering the ranges and variations within properties.

Memos were used in all studies to capture the researchers' thoughts throughout the data collection and analysis, and they guided the continued data analysis and data collection (Corbin & Strauss, 1998). Memos could concern forthcoming codes and categories.

Memos in Study III were, for example, much about crowding and clutter and these aspects were further elaborated in the analysis, e.g. how crowding was experienced and why the store was felt to be crowded. This meant that the researcher went back and forth between the original interviews, photographs and emerging categories.

To enhance the coding process two different software programs have been used. In Studies II and III the Open code was used (Dahlgren, Emmelin, & Winkvist, 2007) and in Study IV the Atlas.ti 7 was used (Atlas.ti, 2012). The use of software programs enhanced and facilitated the constant comparison process of codes and categories. The

software program also facilitated the analysis of film sequences as codes from films could be compared with codes from the focus group interviews (Study IV).

Comparative analysis based on Suchar

In Studies III and IV photos and film sequences were analysed using Suchar's description, which was based on the principles of comparative method by Glaser and Strauss (1967).

In Study III the analysis started with analysing all the different photos from the grocery shop by observing each of them and comparing them to each other. All the different photos were related to each other and sorted into different categories such as entrance, overview of the grocery shop, products and check-out stations in order to facilitate the analysis. The products were further compared to each other later and pictures of products that were related to each other, for example coffee and household items, were sorted together. Photos that lacked focus and duplicated photos were excluded. In total 91 photos were included in the analysis.

In the next step written descriptions were made for each photo. These descriptions included what could be observed in the photo. Memos were written for each photo, consisting of interpretations and previous reflections based on knowledge of the research area. New questions were raised during the analytic process and these were also documented in the memos. During the process of writing memos and descriptions for each photo, photos were excluded when the same aspects were discovered over and over again. One example of a written description for a photo was: *A lot of different vegetables at the vegetable stand, carrots, salads, onions, cucumbers, and tomatoes. At the end of the vegetable stand there are mirrors.* One memo to this description was: *How do people with dementia experience the mirrors when it could create a feeling of many more vegetables?*

Each description and memo was coded line by line and codes were given names close to the written text (Suchar, 1997). To enhance the axial coding, codes, memos and descriptions were inserted into the software program (Dahlgren, et al., 2007). In this step codes were compared to each other and categories were developed (Corbin & Strauss, 1998; Suchar, 1997). These categories were later to be compared with the

categories from the focus group interviews in the same study to create the core category. In Study IV a modified version was used to analyse film sequences, when the original version addressed the analysis of photographs.

In the first step of analysis in Study IV the film sequences were analysed multiple times by observing and comparing them to each other. The different zebra crossings were sorted based on shooting place. Next, all film sequences were systematically analysed by watching them multiple times to get an understanding of what was happening, and what kind of problematic situations could occur for pedestrians in general when using a zebra crossing. Short notes were made in a scheme consisting of notes for each film sequence, for example cars passing, crowding and traffic situations.

To select what parts of the film sequences were to be analysed, recordings were looked through by the research group. The group decided to include five different film sequences with different lengths and conditions of traffic situations. The conditions for included film sequences were: a) evening twilight, traffic light and without traffic island; b) daytime, without traffic signal and with traffic island; c) winter with traffic light; d) four-way junction, traffic island and traffic light; e) a situation with traffic light.

The five film sequences were transferred to the Atlas.ti 7 software program (Atlas.ti, 2012). In the first step of analysis each film sequence was divided into different parts that described problematic situations or action. These parts of the film sequences varied in time. These separate parts were later coded and each part could be comprised of different codes. The codes were created from what was observed in the film and they also described an action or problematic situation. For each code a comment was created comprising a description of what was happening in the film sequences. Memos were written for each code.

In the next step codes were compared with each other and categories were created (Corbin & Strauss, 1998; Glaser & Strauss, 1967). These categories were later to be compared with the categories from the focus group interviews in the same study, and a core category was developed.

FINDINGS

This thesis presents new knowledge about access to everyday activities in public space, as perceived by people with dementia. The findings from each of the four studies were analysed together by using a constant comparative approach (Corbin & Strauss, 1998, 2008). The analysis started with inserting the four studies into the Atlas.ti software program. Thereafter the findings of each study were coded line by line and the coding process proceeded as described above in the method section. This analysis resulted in the categories that are presented below and finally became the core of the four studies. An overview of the core, the categories and subcategories are described in Table 3.

Table 3. Overview of the core category and categories and subcategories.

Core category:
An infinite and unstable process to re-integrate to place
Categories:
The importance of having access to everyday activities in public space
Difficulties related to activities in public space
Problematic situations in public space:
<i>Unpredictable changes</i>
<i>Crowding and clutter</i>
<i>Layout variations</i>
Actions used to get access to everyday activities in public space:
<i>Use of time</i>
<i>Use of familiar spaces and places</i>
<i>Avoiding situations leading to new problematic situations</i>
<i>Getting help from people</i>

The importance of having access to everyday activities in public space

For several reasons, having access to everyday activities was very important for the informants with dementia in the four studies. Being able to do everyday activities and having access to them as long as possible was valued by the informants as it allowed them to perceive themselves as being part of the society and being independent and active persons (Study I). Having access to daily activities as long as possible in public space was considered particularly important when the informants knew that dementia and Alzheimer's disease is a progressive disease, and that their ability to perform activities would be reduced in the future (Study I).

Doing daily activities in public space was associated with how the informants viewed themselves in terms of finding motives for activities in public space, social skills,

perceived competence and self-confidence. The informants valued activities in public space differently then because the meaning of mundane activities was experienced as multifaceted and more important than before. For example grocery shopping was appreciated for the actual shopping as well as for the possibility to take a walk and to be social (Study I).

In public space there were many different places that the informants found to be important such as banks, pharmacies, care centres and hospitals (Study I) and grocery shops (Studies I, II, III), but at this stage the informants preferred these places to be in the neighbourhood. In this way their activity radii had become smaller (Study I) and activities could be abandoned when they were not within walking distance from home. Spaces further away were experienced as unfamiliar and hence avoided (Studies I, II).

Difficulties related to activities in public space

While doing everyday activities in public space, informants could experience different feelings and be confronted by their cognitive shortcomings. The informants could experience problematic situations because they had difficulties staying in control and in focus when doing activities (Studies I, IV). They told of feelings of being exposed and vulnerable (Study I) and feelings of anxiety in public space (Study II), and they had to use extra caution when doing activities there and when crossing a street (Studies II, IV). For example, they had to look very carefully for cars when they did not know if the cars would let them pass at an unattended zebra crossing or if a cyclist would appear suddenly and silently (Study IV).

When doing activities in public space they experienced mental fatigue and this mental fatigue could be experienced even before entering public space because of all the preparatory actions necessary in the home (Study I). The mental fatigue could also be caused by informants' difficulties in relating to every situation in the public space and meeting all the layers of problematic situations (Study IV). The informants also pointed out that they knew that one problematic situation could lead to another one if they failed to act appropriately (Study II). In this way the informants felt that they had to protect themselves from problematic situations, for example by shopping in the morning to avoid the rush hour in the afternoon (Study I).

The informants had difficulties orienting themselves in situations like grocery shops (Study III), going to and from the grocery shop (Studies I, II) and in traffic situations (Studies II, IV) due to problems like impaired spatial ability (Study III). The informants

also had difficulties interpreting and discriminating the diversity in public space such as heavy traffic (Study IV), crowding, clutter and visual illusions (Study III) and noise (Studies I, II, III, IV). Furthermore, discriminating heaps of rubble (Study II) and traffic islands from the pavement (Studies II and IV) could be difficult and could lead to stumbling.

Problematic situations in public space

In public space the informants met a variety of situations. The situations, the persons and places transacted with each other. These transactions could change from moment to moment and from one day to another as the public space was in a constant flux (Studies I, II, III, IV). The transactions between the situations, persons and places could occasionally be experienced as creating a problematic situation. A problematic situation as a whole consisted of different layers that transacted. In Study II, the problematic situations as a whole were found to appear from different critical incidents and in Study IV to consist of different layers added to each other. Informants experienced many different problematic situations when doing everyday activities in public space. This started in the informants' homes with preparatory activities (Study I) and different layers of problematic situations were described such as remembering and finding important things for doing grocery shopping, e.g. wallet and keys (Study II). In public space informants told of problematic situations related to finding the way (Studies I, II, IV) and specifically to finding a safe way through traffic (Studies I, II, IV). Informants also experienced problematic situations related to everyday technology (Studies I, II, III), for example the use of computers (Study I) and self-service check-out stations in grocery shops (Studies I, II, III). Other problematic situations were related to crowded places with high tempo and noise (Studies I, II, III, IV). The characteristics of crowding could be related to a lot of people (Studies I, IV), a lot of cars (Study IV) and a lot of noise that the informants had to relate to (Studies I, II, III, IV). Furthermore, problematic situations were also experienced when many things were available to choose from, for example in the home (Study I) and in the grocery shop (Studies I, II, III). The informants also experienced problematic situations related to the layout in shops (Study III) and traffic situations (Study IV).

In the following, characteristics of the problematic situations will be described.

Unpredictable changes

Unpredictable changes in public space could create a variety of problematic situations for the informants and influence how they experienced access to everyday activities in public space. Because of these changes they could have difficulties in finding the way, for example to and from the grocery shop, in the home and in the grocery shop (Studies I, II, III). One problematic situation occurred when they were to find the way if there were constant changes in landmarks that they relied on (Study I). The unpredictable changes were also related to how objects in the grocery shop were rearranged and it became difficult to find the intended product when the shop was not experienced as familiar and organization was disrupted (Study II). The unpredictable changes were also related to noise, crowding and tempo in public space and traffic density when such aspects were in a constant state of change and could be difficult to predict in advance (Studies I, II, III, IV). Controlling and maintaining order became difficult for the informants due to unpredictable changes. A familiar place could therefore randomly change and become unfamiliar and thereby reduce the person's experience of accessibility.

Crowding and clutter

Crowding and clutter in public space were other conditions that the informants had to relate to, that influenced how they experienced accessibility. The crowding could be related to people in public space e.g. on sidewalks (Studies I, II, IV), at the zebra crossing (Study IV), in the grocery shop (Studies I, II, III) or caused by the density of vehicles (Study IV). Furthermore, crowding could also be related to an abundance of products and information all over the shop, which made it difficult for the informants to choose and find the intended product (Studies II, III). Crowding could also be experienced in the home when the informants often had a lot of objects visible and ready to be used. This situation could lead to difficulties to find important objects for doing activities in public space, e.g. keys and wallet (Study II). Too much clutter and crowding made it difficult for the informants to stay in focus and be concentrated (Study IV). Visual illusions also contributed to the experience of clutter and crowding in the grocery shop. For example, mirrors in the shop created an illusion of more products at the vegetable stands (Study III) and the informant reported trying to pick vegetables from the mirrors.

Layout variations

Layouts were important for the informants when doing everyday activities in public space. Layout variations in different grocery shops created problematic situations (Study III). Layouts differed between shops and there were many different services in each shop, such as post offices and pharmacies (Study III). When the layout differed between shops or was changed within the familiar shop, it became even more difficult for them to find what they needed or find their way through the shop (Studies II, III). A complex layout of a zebra crossing had several traffic lights or traffic islands and offered many options for crossing the street. Such layouts were experienced as too difficult and the informants preferred layouts of crossings that were simpler, such as one traffic light and one lane in each direction (Study IV).

The informants experienced that the public space became less accessible when they could not control it, because its organization was decided by someone else. But in their homes the informants had the possibility to organize and maintain order, and thereby stay in control (Study II).

Actions used to get access to everyday activities in public space

To meet problematic situations when doing everyday activities in public space the informants used many different actions (Studies I, II, III, IV). In doing so, they had to relate to several different layers of problematic situations simultaneously and meet each layer with different actions. However the informants experienced difficulties in meeting problematic situations as a whole when only one layer at a time could be kept in focus (Study IV). Consequently, coordinating the continuous changes in public space was experienced as difficult when a variety of actions had to be done at the same time to meet the problematic situations. The actions used by the informants were related to open-ended reflections, creativity and previous experiences (Study II).

In the following, characteristics of the actions used by the informants to meet problematic situations will be described.

Use of time

The use of time was one characteristic of the informants' actions. Planning what time of the day to perform an activity was very important to experience accessibility and usability of public space. Informants avoided doing activities in the late afternoon and in the evening to avoid getting lost, for example. If they had to do activities at that time of the day they did them together with friends or relatives (Study I). The use of time was also seen in that informants preferred to do grocery shopping in the morning to avoid the rush hours (Study I, III).

The informants could wait some time to avoid crowds of pedestrians at zebra crossings (Study IV). It was also important to informants to have a lot of time at their disposal in doing activities in public space when stress negatively affected the performed activity and could overtake them very quickly (Study II, III).

Use of familiar activities in familiar spaces and places

Choosing familiar activities in familiar spaces and places were also important characteristics of the actions used to meet problematic situations, in order to do activities independently (Study I). The informants went to familiar shops within walking distance from home (Study II), and to cross streets they used crossings that were familiar and not too complex, for example zebra crossings with traffic lights (Study IV). To find a product in the shop, informants often bought the same brands because the packages were the same and therefore familiar (Study II), and to find their way in the shop they always took the same route, thus maintaining their familiarity with its layout (Study III).

Avoiding situations leading to new problematic situations

The informants knew that the actions they used in order to meet problematic situations could fail and that a new problematic situation could occur. Therefore they planned and tried to avoid these situations. This was exemplified by the use of a shopping list as a reminder for knowing what to buy. But if the shopping list was forgotten at home they did not know what to buy in the shop and this could result in going shopping several times in one day (Study II), that is, new problematic situations occurred.

Informants also planned ahead how to pay for their groceries when paying could lead to new problematic situations, as they had difficulties using credit cards and counting

money. They had considerations if they had to use the self-service check-out stations or if the ordinary counter desk was open (Studies II, III). The informants avoided crowding in sidewalks, shops and crossings when they knew from previous experiences that these situations could lead to new problematic situations (Studies I, II, III, IV).

Getting help from people

The informants needed help in some situations to get access to activities in public space, for example help from relatives and friends when doing activities in the afternoon or evening if it was dark outside (Study I) and when doing grocery shopping far away from home (Study II).

When informants got lost in public space (Studies I and II) or did not find products in the grocery shop (Study II) some of them asked other shoppers or staff for help, while some avoided asking for help as they did not want to reveal their diagnoses (Studies II and III). The informants had considerations regarding whom to ask for help. For example they did not ask people who appeared to be in a hurry, and they asked females rather than males, or people who did not seem to live in the area (Study II). The informants also relied on help from cashiers when they had difficulties in counting money; they could hand over their money to the cashier to take the right amount of money (Study II).

Some of the informants tried to get contact with drivers when crossing the street by raising a hand or raising their canes in the air to let them cross (Study II).

Table 4 describes perceived problematic situations and layers of problematic situations and how the informants met these.

Table 4: Perceived problematic situations and layers of problematic situations and how they could be met by the informants in the four studies.

Problematic situations	Layers of problematic situations	Actions used to meet problematic situations
Preparations in home	Remember what to bring and what activity is to be done in public space. Clutter of objects, many objects ready to be used.	Bring a note of what to bring, buy and do. Keep strict order in home to find objects.
In general in public space	Interpretation of signs, timetables and maps. Locate signs. Crowded places with high tempo and noise. Find the way in late afternoon and evening. Replacement of service personnel with everyday technologies (computers, self-service check-out stations). Communications with answering machines and following different steps.	Avoid stressful situations. Regular daily or weekly, space-time patterns in shopping. Take walks in the same places. Do less demanding activities. Do activities together with friends or relatives. Do activities within an activity radius of home
Finding the way	Change of landmarks. Reconstruction of houses and streets.	Choose small shop within walking distance from home. Shop with friends or relatives. Use transportation for old and disabled when going far away from home. Use street signs. Ask people for help.
Crowding of pedestrians	Crowding at the zebra crossing and sidewalks. Chaotic pattern of pedestrians at zebra crossings. Pedestrians do things simultaneously when crossing the zebra crossing	Avoid crowding by walking around it. Wait some time to avoid the rush at green at zebra crossing.
Crossing a street	<u>Layers related to layout.</u> Big crossings with lanes in different directions. Four-way junctions with or without traffic light. Zebra crossings with traffic islands. Green light for both pedestrians and drivers at the zebra crossing. Heavy traffic. Lack of safe crossing in the neighbourhoods. Deviate from predetermined places and walking. Road works. Short time intervals of traffic lights.	Walk longer distance to avoid complex layouts of zebra crossing. Use of traffic lights as a reminder and security precaution. Use of zebra crossing with or without traffic lights. Wait until no cars are coming down the road. Walk with relatives. Be a cautious pedestrian. Signal to the drivers. Follow the flow of other pedestrians.

Problematic situations	Layers of problematic situations	Actions used to meet problematic situations
Crossing a street	<p><u>Layers related to cars</u> Unsure if cars would stop or not. Drivers not using indicators for turning. Gaps between vehicles. Direction of vehicles. Closeness of cars. Cyclist and drivers ignoring traffic rules.</p> <p><u>Layers related to discrimination</u> Discriminate and understand different road markings. Discriminate marks at zebra crossing covered with snow. Discriminate things from each other at the crossing when the colour is the same (grey). Stumble on objects such as traffic islands. Discriminate silent vehicles. Discriminate sounds and what sounds to direct their attention to.</p>	
Grocery shopping	<p><u>Layers related to doing</u> Influenced by people being stressed in the shop, for example the cashier. Packing groceries. Count money. Use of self-service check-out station. Use of credit card. Remember security code for credit card. Choose the right member card. Get through when aisles are crowded.</p> <p><u>Layers related to layout</u> Many different services in grocery shop. Locations of products. Illogical layout of check-out station such as card reader and change machinery for coins. Objects and information all over the shop. Clutter and crowding. Mirrors, glass doors and walls creating visual illusions. Background music and noise.</p>	<p><u>Finding</u> Search for object in an unstructured way. Walk around in the shop to find the intended product. Use of signs to find objects. Take one's time when searching. Talk to oneself. Observe illustrations on products. Buy the same familiar brand of products. Importance of pre-understanding of layouts of shops. Walk the same routes in shop. Go along the walls of the shop. Prefer small shop, but at the same time broad aisles.</p> <p><u>Paying</u> Hand over money to cashier. Pay with a large-denomination bill. Avoid credit cards. Sign receipt when using credit card. Hand over member cards to cashier to choose the right one.</p>

An infinite and unstable process to re-integrate to place

The core, an infinite and unstable process to re-integrate to place, was characterized by the fact that accessibility was experienced as a constantly changing experience. It was also characterized by continuous changes in the relationship between the informants and the public space. These changes were both unpredictable and predictable.

In public space people have to relate to a variety of different situations. Generally these situations are met with different actions and often the actions are done in an unconscious way by the persons and thereby not experienced as problematic. But people with dementia experienced that many situations in public space had become problematic. This was associated to the problematic situations as a whole containing different layers. When doing activities in public space the informants had to relate to and transact with many different layers of situations, as much was going on at the same time. This included sounds from cars, people talking, music, sounds from refrigerators in the grocery shop, different weather conditions, shop layouts and zebra crossings. These different situations transacted and could create problematic situations as a whole. However, the problematic situations as a whole could on different occasions embrace different layers. Therefore one problematic situation in one moment or one day could embrace one set of layers and another day another set of layers, thereby creating a completely new problematic situation. Thus the possible variations in different layers of minor problematic situations creating a larger problematic situation as a whole were unstable. These findings show how the public space and persons are in constant interplay and in constant change. Meeting problematic situations was for the informants an infinite and unstable process of re-integrating to place. They used different actions to meet different layers of problematic situations in order to achieve relative harmony in each problematic situation. The actions used were related to open-ended reflections, previous experiences and creativity. The action to be used could seldom be predicted in advance because circumstances in public space changed continuously and the ever-changing relationship between the environment and person varied. Hence, the challenging process of finding actions to meet critical incidents was unpredictable and never stable, and one critical incident could lead to the occurrence of a new incident. When problematic situations occurred, the relative harmony in that particular situation was influenced. Therefore the informants used different actions to meet the problematic situation in order to achieve relative harmony again. Nonetheless, relative harmony could be achieved in some situations, but not in others, and therefore variations in relative harmony occurred on different occasions when the actions used could succeed

or fail. In some cases the informants could not achieve relative harmony at all by using different actions in the problematic situations and therefore a disruption could occur in their re-integration to place. The disruption in re-integration to place could be exemplified by informants having abandoned activities in an activity radius further away from home when they experienced that they could not manage to re-integrate to place in the situations far from home.

GENERAL DISCUSSION

Findings

Findings from the studies in this thesis have contributed knowledge about what kinds of problematic situations people with dementia experience when doing everyday activities in public space, in particular those related to grocery shopping and being a pedestrian. Knowledge about how they met these situations with different actions and how the process worked to meet problematic situations with actions came to the fore. Furthermore, new knowledge was developed about the relationship between persons and environments by using a transactional perspective. In the following, findings from the thesis will be discussed.

Problematic situations in public space

Findings from this thesis show the importance of people with dementia having access to everyday activities in public space as long as possible (Studies I, II, III, IV). These findings are in line with earlier studies (Duggan et al., 2008; Phinney et al., 2007). Aging persons are supposed to be secure, safe and comfortable within the walls of their homes, and the support offered has mainly been provided within the physical home (Henning, Åhnby, & Österström, 2009; Hwang, Cummings, Sixsmith, & Sixsmith, 2011). However, to age in place also includes aging in public space (Thomas & Blanchard, 2009). This is also of great importance for people with dementia who remain in their ordinary housing (*National Guidelines for Care in Cases of Dementia*, 2010) as they value doing meaningful activities, carrying on with their lives and maintaining normality as long as they can (Ablitt, Jones, & Muers, 2009; Egan et al., 2006; von Kutzleben et al., 2012; Öhman & Nygård, 2005).

Findings from the four studies in this thesis have provided knowledge about activities in public space that people with dementia experience as important, but the focus has been on problematic situations and how they met these, especially when doing grocery shopping and being pedestrians. This is a new way of studying access to activities in public space, in comparison to other studies that have generally shown that activities are important for people with dementia, for example visiting friends, going to the grocery shop and taking walks (Burton, 2006; Mitchell & Burton, 2006). Problematic

situations have often been found to relate to difficulties in interpreting the environment and in navigating (Blackman et al., 2003). However, findings from the four studies in this thesis have illuminated a variety of problematic situations; these have been investigated in a more thorough way and will be discussed in the following.

In the findings, it became evident that a variety of different problematic situations was experienced by the informants. For example they seldom used public transportation by themselves (Study II), and the most common mode of transportation was to walk, i.e. be a pedestrian (Studies I, II, IV). They experienced problematic situations related to crowding of pedestrians at zebra crossings and on the sidewalks, through heavy traffic, complex zebra crossings with many lanes and in combination with traffic islands and noise. They had problems of not trusting drivers to let them cross at zebra crossings (Study IV). Furthermore, crossings with traffic islands were experienced as complex; the informants avoided these and preferred simple crossings with traffic lights. These findings are new in that specific problematic situations are illuminated. Earlier studies have described, for example, that zebra crossings with many lanes created confusion and insecurity for people with cognitive disorders (Nordin Lidberg, 2009). They used non-controlled traffic islands when it facilitated the crossing in two steps (Burton, 2006), but these studies did not focus especially on people with dementia as pedestrians.

Another important finding from Study IV was that zebra crossings with traffic lights seem to be especially important for people with dementia in order to facilitate their participation in public space. This finding could be compared to the traffic solutions that are made in Sweden in order to provide safe crossings for people with cognitive disorders. The ambition is that the traffic situations should be uncomplicated, with short crossings and logical structure (Klaesson, Nilsson, Malm, & Johnni, 2008; Nordin Lidberg, 2009). Such solutions also aim to create safer crossings for the older population in general (Knudsen, 2007; Vägverket, 1999). However, at the same time zebra crossings are removed in order to create safer crossings, as many traffic incidents happen at zebra crossing without traffic lights. This is related to the traffic rule that requires drivers to yield to all pedestrians at an unsignalled crossing (Thulin, 2007). These solutions are in opposition to findings described in Study IV, where the zebra crossings with and without traffic lights were showed to be facilitators for people with dementia doing everyday activities in public space.

Moreover, the findings from Study IV described a variety of different situations that were transacting. Different layers of problematic traffic situations were added to each other and this process could be assumed to explain why the informants experienced crossing a street as problematic when they directed their attention to one layer at a time. This could explain why they experienced fear of being run over when crossing a street. That is, they are not just generally afraid as earlier studies have suggested (Burton, 2006), but the findings from this thesis highlights aspects of their process in meeting problematic situations that can explain their fear.

Another novel finding of this thesis is that all the noise in public space was transacting and the informants had difficulty in relating to every single noise. Hence, all the different layers of noise became problematic for them. They told of noise from cars, background music in shops and people talking. It was not the sound level in particular that was problematic, but all the noises added to each other. The informants had difficulties discriminating sounds from each other and knowing what sound to direct their attention to, for example in the traffic situation (Study IV). Furthermore, the noises influenced how they could concentrate, and noise could create stressful situations (Studies I, IV). On the other hand, the informants could also experience and reflect on lack of noise from cyclists, and in such situations the lack of noise could be experienced as problematic, because a cyclist could suddenly appear as they were about to cross a street (Study IV). These problems with noise are in line with a study showing that people with dementia may have difficulty discriminating meaningless or meaningful hearing cues from each other (van Hoof, Kort, Duijnste, Rutten, & Hensen, 2010). In addition, Ingberg (2010) described problematic situations related to noise when seeing friends or doing activities in public space, as the filter for sorting the noises from each other had disappeared. But earlier research on noise and dementia are commonly still related to nursing homes and interventions to minimize noise level (Brawley, 2001), while noise in public space has received less attention in literature on dementia. One conclusion from the findings of this thesis is that noise plays a very important role in transactions in public space. Therefore noise has to be taken into consideration as an important aspect of accessibility and usability in public space.

A common activity performed by most of the informants in the four studies was grocery shopping. Findings from the thesis identified different problematic situations in the grocery shop. These situations were described as difficulties in finding products

when rearrangement of products had occurred, in using a credit card and in counting money. Other problematic situations were related to different services in the shop, such as illogical layout of check-out stations, clutter and crowding and visual illusions (Studies I, II, III). To date there are few studies that have described what kind of problematic situations people with dementia experience when doing grocery shopping although it has been suggested that grocery shopping is difficult for people with dementia (Liu et al., 2007). However, findings from the thesis could on the one hand be compared to those describing problematic situations experienced by older people in general, for example crowding in shops (Eroglu et al., 2005; Machleit et al., 1994; Pan & Siemens, 2011) and change of store layout (Meneely et al., 2008). On the other hand, though, the informants in this thesis were much more sensitive to changes (Study II) when many layers were transacting and influencing how they experienced a shop as accessible and usable. The findings from Studies II and III also indicated that the informants became increasingly sensitive to stress when doing grocery shopping; this was exemplified when paying for their groceries. What came to the fore was that people with dementia need to do activities at their own pace to avoid problematic situations. One lesson learned from these findings is that people with cognitive disorders such as dementia should be allowed to do things in their own pace. One suggestion is to introduce a slower check-out station in grocery shops where people could act at their own pace, as a complement to the express check-out stations and ordinary check-out stations.

The problematic situations in the grocery shop described in this thesis could also be discussed from the store managers' perspective. The goal for store managers is to sell as much merchandise as possible and one way to achieve this is to rearrange products in the store. These arrangements are based on different product-display principles (Larson, 2006). Another strategy is the use of background music (Vida, Obadia, & Kunz, 2007). But such rearrangements of products and background music did not match people with dementias' experience of a shop as being accessible, as they preferred products to be placed at the same place all the time. Noise could create a stressful situation. However, it is of great importance that store managers obtain knowledge about potential consequences of re-arrangements and background music with which they can produce grocery shop that is inaccessible for some customers. Store managers could benefit from knowing what kind of problems people with dementia might experience when doing grocery shopping and why some customers

may act in different ways, for example, when having difficulties paying for their groceries. Pettigrew et al. (2005) also suggested that staff working in shops ought to be trained to interact positively with older customers. These findings give further reinforcement to those of a study that showed that people with dementia in England, Wales and Northern Ireland believed that their lives would be improved if the community had a better understanding of what it is like to live with dementia, as they did not feel that they were part of their community and did not have a voice there (Lakey, Chandaria, Quince, Kane, & Saunders, 2012). This is important to reflect upon; a new term has emerged in recent years – “dementia-friendly communities”, to highlight these issues. It reminds the society that people with dementia have the same rights to be treated with respect and dignity, and to continue to be active citizens in public space (Mitchell, 2012). Similarly, the United Nations has emphasized the importance of providing equal opportunities for people with disabilities to be able to participate in community and social life (United Nations, 1993). One step towards creating a more accessible and usable public space is to obtain knowledge of how people with dementia experience these issues, and this has been in focus in these four studies.

In this thesis public space has been viewed as the space outside the home and the space where the problematic situations occurred. However, in Study I, the informants spoke of problems of using the Internet, and they reflected that today many services are available only on the Internet. Furthermore, in Study II the activity of grocery shopping was also associated with activities in the home. On the one hand public space has been seen as the space outside the home, but on the other hand activities done in public space were initiated already in the home. Findings from Study II indicate that the activities done before doing activities in public space were also transacting with public space. For example the informants often had to search to find the right objects before going out, such as keys and wallets, and sometimes they felt mentally fatigued even before entering the public space. Findings from the thesis suggest that the public space may not just be the space outside the home, but may also be extended to include the internet and even the home. This argumentation is in line with findings as early as 1997, that cyberspace is a new public space (Jones, 1997), but the novelty is that the home also has to be taken into account for people with dementia doing everyday activities in public space.

One important finding from the thesis emphasized that the informants with dementia had difficulties transacting with situations going on in public space and coordinating with the environment; this influenced how they experienced the public space as usable and accessible. Findings also suggested that each situation was not static but constantly changing and so was the person; for example mood, mental fatigue and cognitive ability fluctuated. Situations occurred in infinite irregular patterns and it seems nearly impossible to predict what kind of situations would occur on a particular occasion when a person is doing activities in public space. To understand what kinds of problems and challenges the informants experienced when doing activities in public space, the situation as a basis of human action (Cutchin, 2004) contributed to the development of new knowledge of how to understand the complexity in the relationship between persons and public space in this thesis.

Hence, in the following actions used to meet problematic situations will be discussed.

Meeting problematic situations

An important finding from the studies was that the informants valued being a part of society. However, to be a part of the public space the informants had to meet many different problematic situations by using their own actions. Previous research has also found that it is important that people with dementia can participate in their local communities (Mitchell & Burton, 2006). However, findings from this thesis add new knowledge about the process of meeting problematic situations in public space. The informants in the four studies described and exhibited many different actions they used in order to achieve relative harmony in each problematic situation in public space. The actions were often self-initiated and often based on creativity and habits. The informants usually went to the same shop in the neighbourhood (Study II) and did activities at specific times of the day to avoid crowding (Studies I, II). In other words, they seemed to use familiarity and habits to maintain access to everyday activities in public space. This is in line with earlier research that described the management of changes in everyday occupations in dementia (Nygård & Öhman, 2002). Habits could in one way be described as behaviours that are repeated so often that they become habitual and are performed on a preconscious and automatic level. In a familiar environment habits are more likely to occur and serve the purpose of conserving energy while the person does activities (Christiansen, 2005). According to Dewey, habits give the person stability and continuity to act, freed from the need to think through and

decide on a plan of action in each particular situation (Campbell, 1995). It has also been argued that habits arise from participation in the world and therefore habits cannot be viewed as internal to the person. The more habits the person has at his or her disposal, the more potential he/she has to employ different habit configurations in relation to a situation and in response to changes in the situation (Cutchin & Dickie, 2012). The findings from this thesis showed that the informants had difficulties in meeting layers of problematic situations at the same time, as they directed their attention to one layer at a time. One interpretation of these findings is that they had many habits at their disposal, but with the progression of dementia it became more difficult to use habits without consciously attending to what they were doing. In other words, a habit became non-habitual. Therefore, it is likely that if people do not have access to everyday activities in public space their habits cannot be maintained or developed and they will be excluded from participating in the public space. This underscores the importance of maintaining activities in public space as long as they are of interest to the person with dementia.

Interestingly, in the four studies in the thesis, the persons with dementia acted as problem solvers in order to get access to everyday activities in public space. Some informants made active choices in meeting the problematic situations while others followed the flow of other pedestrians to cross a street at the zebra crossing (Study IV). These findings are in line with Dewey's suggestion that humans are problem-solvers who can use reflective abilities to overcome ongoing difficulties in life, even without ultimate success (Campbell, 1995). This way of reasoning could be applied in facilitating access to everyday activities in public space. For example, it could be suggested that relatives, family members, carers and medical professionals could pay attention to and support ways of meeting problematic situations used by people with dementia before trying to teach new strategies to them. This is in line with a recent study that found that people with dementia appreciated support that allowed them to stay in control (Fetherstonhaugh, Tarzia, & Nay, 2013). This support involved forming strategies and plans together in order to enable them to do activities independently. The informants in Fetherstonhaugh's study appreciated the ability to hold on to their decision-making abilities as long as possible. However, when doing activities in public space where many different situations occur simultaneously, the persons with dementia are exposed to many hazards and their safety could be threatened (Study II, IV). According to Gilmour (2003), relatives and family members described risks that they

worried about to the person with dementia in public space. Such risks included falling, road safety incidents, lack of money management, and getting lost (Gilmour, Gibson, & Campbell, 2003). From the relatives' perspective it is easy to understand that they could experience a challenge in letting their relatives with dementia do activities independently in public space.

However, in this thesis the informants described and also showed in the observations that they were aware of problematic situations in public space (Studies I, II, III, IV), but they also said that their awareness could fail when only one layer of the problematic situation was in focus at a time (Study IV). This was also observed in traffic situations, when the observer had to intervene (Study II). This is in line with studies that showed that people with dementia are far more aware than has been assumed in earlier research (Clare, 2003; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Öhman et al., 2008). Furthermore, if the person has good self-awareness this could facilitate the use of different strategies (Suchy, Kraybill, & Franchow, 2011). Earlier research has showed that people with dementia may have loss of insight and be unaware of illness, meaning that they are frequently unaware of their cognitive symptoms (Ecklund-Johnson & Torres, 2005). However, findings from this thesis indicate that informants were aware of problematic situations in public space to a great extent, and this awareness has to be taken into consideration when interventions are planned to facilitate access to everyday activities in public space for people with dementia. This conclusion is supported by Öhman, who suggested that awareness should be individually evaluated when planning interventions for people with dementia (Öhman, Nygård, & Kottorp, 2011).

Sense of familiarity in public space

One important finding in the thesis was that familiarity with activities, spaces and places was important in order for the informants to experience them as accessible and usable. Another finding was that familiarity with activity and space changed over time. The informants experienced a place as familiar when they felt safe and comfortable doing activities there (Study I). But as the disease progressed their activity radii little by little became smaller, and they did not feel safe in places further away from home, thus these places became unfamiliar (Studies I, II, IV). These findings add new aspects to the findings from other studies showing that activities are done in the neighbourhood (Burton, 2006; Duggan et al., 2008; Oswald et al., 2010) and that unfamiliar

environments limit people with dementia from doing everyday activities in public space (Blackman et al., 2007; Duggan et al., 2008).

“Activity radius” was elucidated in this thesis as an important aspect for the informants to be able to perform activities in public space independently, and it was used to describe the geographical radii from the base of the informants’ homes where everyday activities were performed (Study I). This term is similar to the term “action range” used in a study that investigated in which areas older people with and without cognitive decline moved and performed activities (Oswald et al., 2010). The informants’ activity radii were often located in the neighbourhood. Neighbourhood is a concept often used when referring to the familiar and close environment to which people with dementia relate (Blackman, 2006). But the perception of neighbourhood and familiar and close environments varies between individuals in general from being, for example, local town centres to single streets (Smith, Gidlow, Davey, & Foster, 2010). In the studies in this thesis activities that informants had access to were performed in activity radii near their homes.

The findings reveal that informants were very sensitive to changes in neighbourhood, and these small changes transformed the space and place, making them become unfamiliar. This was exemplified when a house had been repainted (Study I), regarding rearrangements in the shop or when the layout of a product had changed (Study II). The findings from the studies in this thesis suggest that people with dementia are also aware of and sensitive to small changes in the public space. According to Philips (2013), places could also become unfamiliar when changes occur and another study suggests that familiar spaces could become unfamiliar due to cognitive decline when the place conveys no sense of attachment, emotion and identity (Phillips, Walford, & Hockey, 2011). Another aspect of unfamiliarity described by Burholt (2006) was that when a space was experienced as unfamiliar it lost its status as a part of the person’s daily routines. Interestingly, the finding that the informants were very sensitive to small changes in public space could be compared to the finding of another study showing that people with dementia were less aware of changes in their local neighbourhood, but when they discovered the changes they became confused (Burton, 2006). It could be assumed that if people with dementia are sensitive to small changes in public space, they must have the opportunity to encounter these small changes repeatedly in order to experience them as familiar and not confusing.

Findings from this thesis indicate that people with dementia seemed to make places into spaces when they abandoned places that were earlier meaningful and familiar. This was exemplified by the fact that places that had a specific meaning for the informants had today turned into spaces where they did not feel safe, familiar and in control. These are contradictory to Rowles's (2013) findings concerning the process of making spaces into places. He has pointed out that over the life course there are ongoing processes of making spaces into places. A place is a space with cultural understanding and social meaning. In this way the sense of place transforms the spaces (Rowles & Bernard, 2013). Furthermore, through the process of habituation each place leaves marks in the person and becomes imbued with significance as a component of the person's ongoing life. One conclusion from the findings regarding familiarity in this thesis is that, in order to maintain a place as familiar it was obvious that the informants had to stay and do activities in the place. It is of great importance to develop a better understanding of the perceptions of people with dementia of familiar and unfamiliar places, keeping in mind that the perception of familiarity with places may change as the disease progresses (Studies I, II, IV). Therefore it is important that relatives and staff who work with people with dementia living in ordinary housing are aware that the public space has to be incorporated into their everyday activities in order to maintain familiarity with space and place (Study II).

Accessibility and usability

Findings from the thesis suggest that people with dementia experience accessibility as a constantly changing experience when the situations, places and persons transact and are in constant flux. Findings also suggest that accessibility and usability could be jointly used, because in order to experience accessibility the person also has to be able to use the public space (Study I). This was illuminated in Studies I and II, when people with dementia experienced the shop as accessible regarding objective standards and norms for getting in and around, but that the shop was not usable when they, for example, could not pay for their groceries, i.e. the informants described problematic situations mainly related to usability aspects. These findings add aspects of understanding to the regulations for how to create a more accessible public space in Sweden for people with reduced mobility or orientation (*BFS 2013:9 HIN 3.*, 2013; Didón et al., 1987). In 2010 a regulation was issued in Sweden to make public places accessible for everybody, meaning removal of easily eliminated obstacles such as steps at entrances to shops and

introduction of easily read signs (*BFS 2013:9 HIN 3.*, 2013). It may not be so remarkable that interventions regarding accessibility have mainly been viewed from a physical point of view and therefore standards and norms are focused on these aspects (Nations, 1993). However, the findings from this thesis suggest that people with dementia experience different problematic situations, and regulations regarding accessibility should take notice of cognitive accessibility to a greater extent.

In this thesis no instrument for objectively assessing problematic situations has been used, because the focus was on how people with dementia experienced accessibility and usability in public space from the subjective perspective when doing everyday activities. It must be emphasized that to date there are many instruments and approaches for measuring accessibility problems (Iwarsson, 1999; Reinhardt, Miller, Stucki, Sykes, & Gray, 2011). However, the instruments commonly used assess accessibility problems in the housing environment and the immediate outdoor environment (Iwarsson, 1999). These instruments have their focus on accessibility regarding environmental demands and functional limitations, and are objective in nature (Carlsson et al., 2009). This is no problem when physical aspects are assessed, but it becomes more complicated when cognitive aspects of accessibility are in focus. Furthermore, the layers of problematic situations that the informants described were mainly subjective, and their subjective experiences could change from one day to another, for example how they experienced crowding, cars and noise.

A challenge in future research would be to create an interview questionnaire that captures the subjective experiences of people with dementia of accessibility and usability in public space. This is of great importance, as the findings from this thesis emphasize that people with dementia may experience other problematic situations than do older people in general. Few physical obstacles come to the fore in this thesis as problematic situations except for some informants who stumbled on traffic islands and heaps of gravel (Study II) and some who had difficulties using the zebra crossing with a walker when several people were crossing at the same time (Study IV). These findings could be compared to studies of older peoples' perceptions of barriers in public space that are often linked to outdoor mobility and physical barriers, for example irregular walking surfaces, differences in curb levels and lack of benches (Iwarsson, Ståhl, & Löfqvist, 2013; Rantakokko et al., 2012; Rosenberg, Huang, Simonovich, & Belza, 2013; Valdemarsson et al., 2005). On the one hand it may not be seen as surprising that the informants did not experience many physical barriers, when the main concern in the

thesis was issues related to dementia. However, they probably also experience symptoms related to normal aging, such as mobility problems and reduced balance (Rundgren, 2006) and it could be assumed that physical barriers may also be experienced during the aging process.

Different disability groups have different demands regarding accessibility and usability in public space, for example wheelchair users (Welage & Liu, 2011) and people with visual impairments (López, 2005). Hemmingsson (2002) described three different levels of adjustment in the environment: general, group and individual levels (Hemmingsson, 2002). By using these levels, the understanding of whom an adjustment would benefit can be illuminated. Interventions for facilitating a more accessible and usable public space for all are most often done on a general level through regulations by standards and norms, and should not be based on individual assumptions (Iwarsson & Ståhl, 2003). It could be assumed that interventions on group and individual levels could be difficult to accomplish in public space, as for example the grocery shop is public. However, it can be assumed that many people in public space could benefit if the public space would be made more dementia-friendly, for example by designing slow check-out stations to be easily used in shops and by clear and instructive organisation of public space.

Challenges to using a transactional perspective

In this thesis the transactional perspective has been used. By using this perspective, deeper insight has been reached into how people with dementia experienced accessibility and usability to everyday activities in public space. But using this perspective has also led to some challenges that need to be discussed.

One of the challenges was to describe the person and the environment as being part of each other, in a constant interplay and the constant change of situations (Dickie et al., 2006). Even though the goal in this thesis was to use a transactional perspective, the dualistic view of cause and effect could be traced in places. In Study I, for example, the core category was formulated as accessibility as a constantly changing experience. A metaphor for this was the kaleidoscope. Here the categories of properties and dimensions were inseparable and interpenetrating each other. However, when changes occurred a new symmetrical geometric design appeared. Critically examining this, it could be assumed that a cause and effect was described when some occurring changes

created new inseparable connections. However, what is important to highlight in the transactional perspective is that the new inseparable connections that continuously occur do not stand by themselves, but are seen as part of each other. The description of layers of problematic situations and actions used to meet these in Table 4, in the thesis summary, could also be interpreted as cause and effect reasoning. But the intention was not to view them in a linear way, meaning that the described layers of problematic situations had to be met with the described actions. Instead these are examples of how the informants described their experiences in these particular situations. Another day these situations could consist of different layers of problematic situations and actions. In other words, different layers are transacting in different situations. However, the challenge is still to describe the transactional perspective in research without using a dualistic view of cause and effect, and to describe the complexity of the transactional perspective in research in a clear and simple way. However, if the transactional perspective had not been used in this thesis I claim that it would have been difficult to obtain knowledge about how problematic situations could be met with actions. The transactional perspective has added another perspective on how to understand accessibility and usability.

Methodological considerations

Sampling

In this thesis the principles of purposeful sampling strategy were used. This means that the informants who were included could inform with an understanding of the research problem (Creswell, 2007; Patton, 2002), which in this thesis was how people with dementia experience access to everyday activities in public space.

The Mini Mental State Examination (MMSE) (Folstein et al., 1975) was used to describe demographic information of the informants in Studies I and II. MMSE is the most frequently used instrument in screening for cognitive impairment (Ismail, Rajji, & Shulman, 2010). MMSE was not used in the inclusion criteria in the studies. The informants in Studies I and II scored between 18 and the maximum score of 30, indicating mild to moderate impairment (Jönsson & Wimo, 2009). All of the informants experienced difficulties in doing activities in public space regardless of their MMSE scores. In Studies III and IV MMSE was not used, as the instrument did not contribute important data regarding the experiences in Studies I and II. This choice

could on the one hand be questioned when we found that informants in Study IV had different abilities to discuss the film sequences. In this case it could have been appropriate to use the MMSE to screen for impairment. On the other hand, even if they had scored low on MMSE, they were still pedestrians and their experiences were important for the study.

The informants with mild and moderate dementia in this thesis manage to do several activities in public space by themselves. Notably, this is not in line with earlier literature on stages where people in mild dementia are said to be dependent on others when doing community activities (Hughes et al., 1982).

Data collection

The public space is an important aspect in this thesis and different data collection methods were used to get access to the experiences of people with dementia of everyday activities in public space. The methods included individual in-depth interviews, observations, photo documentation and focus group interviews with photo elicitation. These methods will be discussed in relation to public space.

Individual interviews

In Studies I, II and IV individual interviews were performed in informants' homes to illuminate different aspects of their experiences of doing activities in public space. It could be questioned whether individual interviews were an appropriate method for studying experiences of public space for people with dementia, as decline of memory function is common. Moreover, interviews rely on verbal and cognitive functions and people with dementia may have difficulties in recalling events and talking about abstract issues (Hubbard, et al., 2003). But the informants had no apparent problems in recounting experiences regarding accessibility and usability in public space related to performing activities, and the interviews gave a broad picture.

In Study II parts of the interviews from Study I were used, and this could be seen as a limitation when no new interviews were done with the specific aim of Study II.

However, in the analysis of data in Study I, much data was discovered that dealt with problems when doing grocery shopping and how the informants met these problems with different actions. These data were not elaborated in depth in Study I and were therefore chosen to be the basis for the data analysis in Study II. To get deeper

knowledge about critical incidents when they actually occurred, observations and interviews with people with dementia when they actually did grocery shopping were added (Study II). Combinations of interviews and observations have been recommended when doing qualitative research with people with dementia (Nygård, 2006).

Interviewing people with dementia can be challenging. The interviewer was alert to the person getting tired, and small talk could allow the informant to rest. Another option was to continue the interview another day (McKillop & Wilkinson, 2004; Nygård, 2006). When the interviews were done the informants said that they had appreciated having someone listen to their thoughts and indicate that their experiences were valued. This is in line with a study that showed it was important that the informants felt that they had accomplished something and got a sense of achievement from participating in research (McKillop & Wilkinson, 2004).

Observation

In Study II participant observations were performed by two observers when informants went grocery shopping. Doing observations with two observers is a common research strategy. In a study by Mitchell and Burton (2006) two researchers performed accompanied walks with people with dementia in their neighbourhood, in the same way as in Study II. This is in line with Keady et al. (2012), who suggested this method to be appropriate when the aim is to get access to the experiences of people with dementia of public space.

How many observers to use in a study must be related to the aim of the study (Nygård, Borell, & Gustavsson, 1995). The focus in Study II was on critical incidents and how people with dementia met these, also taking the situations into account. Therefore it could be difficult for one person to observe the multitude of transactions in that particular situation and critical incident and at the same time pose questions to the person doing grocery shopping.

The two researchers recorded everything digitally when doing the observations in Study II. When starting analysis of the digital recordings it was discovered that the researcher unconsciously sorted out a lot of noise in the public space and that much of that noise had been unnoticed by both observers. This was a very valuable experience

during the data collection, when the aspects of noise were found to be obstacles for the informants when doing everyday activities (Studies I, II, III, IV). Background noise has been found to be important in observations when it helps the researcher to conceptualize the recorded conversation after the observation (Negrón, 2012).

Moreover, the sounds in the background provide details about the public space, for example car traffic, music and movements of people. The aspect of background noise could in some studies be valuable data, but at the same time it could be difficult to distinguish noise from the person's speech. Therefore it is important to choose a digital recorder in considering what kind of recorded sound is important for the research (Negrón, 2012).

Observation of grocery shopping also included the interaction with traffic situations on the way to and from the store; some of the informants were exposed to dangerous situations and the researcher had to intervene. Therefore observation in Study IV was not considered to be appropriate when it could be dangerous to expose the informants to different complex traffic situations at crossings. Instead film sequences were used as triggers in the focus group interviews. In this way the informants could discuss crossings of different complexity, without the risk of harm. But data from informants observing film sequences are not the same as observing informants in actual traffic situations. Our choice places great demands on an informant's ability to empathize with the film sequences, but still rich data from the method was achieved. Another method to avoid people being exposed to risk and harm in real traffic situations would have been to use simulated road environments in laboratories (Lobjois & Cavallo, 2009; Neider et al., 2011; Oxley et al., 2005). However, in using this kind of environment other validity problems would occur as the laboratory environment is simulated.

Photo documentation and photo elicitation

There are many different data collection methods within qualitative research, and using visual methodologies is one way to develop an understanding of issues like the physical and symbolic meanings of the built environment (Harper, 2002; Prosser, 2007) and to involve the public in generating understanding of community, consumer and health systems' strengths and problems (Lorenz & Kolb, 2009). In this thesis photo documentation, photo and film elicitation were used in the data collection and analysis.

These methods were seen as appropriate when the aim was to study how people with dementia coordinate with the public space.

A photograph is a snapshot of reality and captures a particular moment. It contains no knowledge of what happened before or after that moment (Moore et al., 2008). In Study III photographs were used as triggers in the focus group interviews, with the intention to inspire the informants to express their experiences of doing grocery shopping in their ordinary grocery shop and also to discuss aspects that stood out in the particular photo. In this way the photos did not just capture a particular moment, but also captured experiences of past, present and future aspects of doing grocery shopping. The photographs also triggered discussions that were not connected to the particular photo, for example visual illusions and noise in the shop (Study III).

The use of photo elicitations was seen as valuable because the photos (Study III) and film sequences (Study IV) gave the informants something in common to discuss. From the photos and films they could also relate to their own familiar shops, their experiences of being shoppers and their own crossings. Thus in summary the informants could illuminate their experiences by looking at photos and films (Hurworth, 2003). This is in line with the literature, proposing that photography can be used as a method to illuminate human experiences (Rose, 2007). The use of photographs offers a way to capture everyday events that could be missed, and when using photo elicitations these events could be discussed and reflected upon in the interview situations (Enzman Hagedorn, 1996). Furthermore, photos may inspire recall of memories and feelings (Harper, 2002). Photographs may capture taken-for-granted aspects of the informant's community and prompt the discussion (Clark- Ibáñez, 2004) and facilitate understanding of the interplay between people and their built and natural environments (Moore et al., 2008; Van Auken, Frisvoll, & Stewart, 2010). However, one lesson learned about using film sequences as triggers for people with dementia was that the sequences should be short. In addition, the informants must have the opportunity to see the same film sequences several times, as they could have difficulties staying in focus. In Studies III and IV the photos and film sequences were used as triggers in the focus groups, which worked well when the informants facilitated the discussions for each other.

However, there are other ways of producing photos when using photo elicitations such as using those taken by informants, or using existing photos (Moore et al., 2008). What kind of photos to use had to be decided when planning for the study (Van Auken et al., 2010). There are limitations related to how the photo elicitations were performed in Studies III and IV as AB took the photographs and made the film sequences; the informants did not choose these. Even though AB produced the photos and film sequences, discussions were held within the research group about what kind of situations could be portrayed, and photos and film sequences were carefully chosen according to the aim of the study. This is in line with an earlier study considering the importance of judging what kind of photos to include (Cappello, 2005).

An alternative method would have been that the informants had made the photos, as in a study where the informants took photos that expressed their feelings about the store and meant something important to the respondent (Kent & Kirby, 2009).

Another method in which the informants take the photos is photo voice. But photo voice has a different goal – to promote critical knowledge and dialogue about important community issues through group discussions of photographs. A further goal is to enable people to reflect upon their community strengths and concerns and finally to reach policy makers (Wang & Burris, 1997). When reflecting on these goals of photo voice, it could have been an appropriate method in this thesis, as aspects in the community regarding accessibility and usability aspects for people with dementia were in focus. But expecting people with dementia to use cameras in order to document the reality of their lives could be hazardous, as they often have difficulties in using just such everyday technologies (Malinowsky, Nygård, & Kottorp, 2011). The informants in Studies III and IV did not have difficulties in talking about the photos and film sequences. However if people with dementia cannot make their own photos the photo voice method is not suitable even if they could talk about the photos to communicate their life perceptions and experiences (Wang, Cash, & Powers, 2000). Using photo voice with people with dementia is unusual, but it is viewed as an exciting tool in doing research together with the informants in participatory action research (Wiersma, 2011).

Many considerations were made before the photos and film sequences were created in Studies III and IV. The researcher used a digital system camera with film recording function. The photographs and film sequences were taken from a standing eye level. These aspects have been regarded in another study as a way of maximizing the validity of photos (Rodiek & Fried, 2005).

How to present the photos for the informants is another important aspect. In Study III the photos were presented on a computer screen and each informant also received an A4-sized photo if they had difficulties in viewing the photo on the screen. The photos were printed on glare-free paper. These arrangements were in line with another study, although there they presented the photos in bound booklets (Rodiek & Fried, 2005). In this thesis, one photo at a time was given to the informants when changing photos on the computer screen. This was done to avoid having the photos mixed up by the informants, and to assure that the same photo was discussed by the informants. This could have been difficult if the informants had photos in bound booklets as suggested by Rodiek, as in this case they could feed slides at their own pace.

Focus group interview

In Studies III and IV focus group interviews were performed in which the interest was in informants' shared experience of problematic situations and how they met these, in their roles of being grocery shoppers and pedestrians with dementia. This is in line with the aim of focus groups, to investigate what informants think and to uncover why they think as they do in a non-threatening environment (Morgan, 1997).

In a focus group the informants are encouraged to ask questions of each other, talk to each other and make comments on each others' experiences (Kitzinger, 1995), and the moderator facilitates the discussion (Barbour, 2005; Krueger & Casey, 2009; Litosseliti, 2003; Morgan, 1997). In Studies III and IV the moderator had different roles. In Study IV the moderator had to pose many questions in one of the focus groups when the discussion between the informants did not continue. The questions were posed to the group and not to an individual, as recommended (Ivanoff, 2002). This experience illustrates that it can be difficult to include informants in the discussion if they do not have questions directed to them individually or if the questions are very abstract. The moderator also had to both observe and listen in order to include all of the informants in the focus group discussion (Litosseliti, 2003). The assistant moderator had an important role in getting the informants to feel comfortable as well as in taking notes and asking additional questions (Krueger & Casey, 2009).

The size of focus groups is discussed in the literature and it is often recommended to have five to ten participants (Krueger & Casey, 2009). The sizes of the groups in Studies III and IV were small, i.e. three to four informants. These small numbers facilitated the discussion, and all of the informants' experiences, standpoints and different views came to the fore. The sizes of the groups are in line with those in other studies in the fields of aging or dementia, where focus groups with three to six participants have been found to be suitable, as it enabled the participants to be involved in the discussion (Boman, Nygård, & Rosenberg, 2013; Ivanoff, 2002; Rosenberg et al., 2012; Vik, Lilja, & Nygård, 2007).

Data analysis

How many interviews, observations and focus groups there were to be was not determined in advance in the four studies. Instead the data analysis continuously guided what kind of data was to be collected and how many informants to include, following the principles of grounded theory. One critical aspect to discuss is when data is saturated. It has been stated by Corbin and Strauss (2008) that data collection could continue forever, as new categories could be added and existing categories could be elaborated upon. It is of great importance that the researcher is responsible for having the categories sufficiently well developed and accept what has not been covered in the study as a limitation (Corbin & Strauss, 2008). In this thesis, data was considered to be rich enough when categories were well defined, but saturation was not explicitly the goal. This is no doubt a limitation.

Little has been published regarding how to analyse photos. In this thesis photos and film sequences have been analysed according to the principles of Suchar (Suchar, 1997), as he grounded his analysis on grounded theory. This was considered an appropriate method because grounded theory was used in all other analyses and therefore it was not a problem to do the constant comparison with the different data sets such as focus group interviews and photo and film documentation.

Many different software programs are available today to analyse qualitative data in research. In this thesis Open code (Dahlgren, et al., 2007) and Atlas.ti 7 were used in the analysis of interviews, and Atlas.ti 7 was used in the analysis of film sequences. When using software programs there are specific aspects that require attention. There is

a problematic link between the procedures of software programs and qualitative analysis and these aspects could have a negative effect on novice qualitative researchers (Peters & Wester, 2007). One trap when using software programs is that the researcher may just put fixed labels on data and put data under those labels (Corbin & Strauss, 2008). Another important aspect, as Hwang (2008) states, is that the researcher still has to do the intellectual tasks, i.e. the software does not do the work automatically. But the use of software programs can make your work better and save time. To avoid these traps the codes and categories in this thesis were constantly compared with the original texts, photos and film sequences and an ongoing discussion of emerging categories was held between the authors. As mentioned by Corbin and Strauss (2008) *“Thinking is the heart and soul of doing qualitative analysis. Thinking is the engine that drives the process and brings the researcher into the analytic process”* (page 163).

In Study IV the Atlas.ti 7 software was used for analysis of the film sequences. This facilitated the analysis as data from film sequences could be compared to individual and focus group interviews, and this process became time-saving. The program also offers analysis of photographs and it could thereby have facilitated the analysis of photographs in Study III.

Critical Incident Technique

The CIT is described in five different steps (Butterfield, Borgen, Amundson, & Maglio, 2005; Flanagan, 1954), and these steps were also followed in Study II. The first step is about determining the general aim of the activity being studied. In Study II the person was expected to accomplish grocery shopping. The second step is to set specifications and plans. In Study II the specific situations to be observed were not determined before collecting data. Instead these situations were discovered during the observations, because knowledge about what kind of critical incidents people with dementia would experience was not available. In the third CIT step the data is collected, in Study II from observations and interviews from Study I. The fourth step is to analyse the data. One common way to analyse data is to count critical incidents and create categories of them, but no particular method of analysis is described in the method. In Study II the principles of grounded theory were used to analyse critical incidents when the focus was not on *how many* different critical incidents that occurred, but instead on *how* they occurred. The last step in the CIT is to interpret and report the data, and in Study II a scientific article was published.

Validation strategies

To secure validation in the studies, different strategies have been used. Firstly, peer reviews were used (Creswell, 2007), utilizing members in the research group with specific knowledge about subjects like dementia and methodological aspects. Critical readers posed questions regarding data collection, analysis and conclusions. This could take the form of discussing interview guides, as well as what photos and film sequences to analyse and include in focus group interviews and in the analysis process to fill gaps within categories. Secondly, rich descriptions such as quotes have been used in the articles to allow the reader to make a decision on whether the findings could be transferred to other situations and settings (Creswell, 2007). Thirdly, triangulation of qualitative data sources was used, meaning cross-checking and comparing data from different collections (Patton, 2002). This was exemplified in Study II when observations and interviews were compared and analysed together, as well as in Study III comprising photos and focus groups interviews and in Study IV's film sequences, individual interviews and focus group interviews.

Ethical considerations

All the studies in this doctoral thesis were approved by the Regional Ethics Committee in Stockholm, Sweden, which had no objections to the studies in this doctoral thesis (ref nr 2007/903-31).

Nowadays it is very common to include people with cognitive disorders such as dementia in qualitative research (Hubbard et al., 2003; Kitwood, 1997; Nygård, 2006). When including people with dementia in research many ethical considerations are discussed in the literature such as how to include informants, how to achieve informed consent and particular ethical considerations in connection to qualitative research (Clarke & Keady, 2002; McKeown, Clarke, Ingleton, & Repper, 2010; Sherratt, Soteriou, & Evans, 2007). All of the studies in this thesis have included people with dementia as informants and ethical considerations have been raised during the research process. Some of the aspects will be discussed in the following.

Oral and written information were given to the informants in the four studies in this thesis. When information is given it is crucial that the informants understand the meaning of the participation in a study. It has been argued that informed consent could

be difficult because of cognitive impairment (Kane, 1998), but it has also been found that people with mild dementia can understand the meaning of informed consent (Buckles et al., 2003). All of the informants gave their informed consent by themselves in the four studies. To ensure that the informants had understood the information and meaning of the study, they were informed repeatedly about the aim of the study and reminded that they had the right to withdraw their participation at any time without any particular reason during the data collection process (Richards & Morse, 2007). When including people with dementia in research the consent may be seen as an ongoing process (Bartlett & Martin, 2002; Dewing, 2007). The oral information about the study was in the form of a conversation and the researchers tried to express it as simply as possible and to repeat the same information in different ways (Patton, 2002). Informants could pose questions whenever they wanted. In one case during a telephone conversation one informant used a speakerphone so the relative could hear the conversation and help the informant to remember the conversation.

To protect the informants' integrity and autonomy is important (Smith, 2008). The individual interviews and observations were performed on a day and time that the informant preferred. It was important that our visits should not influence the informants' daily activities when they had scheduled activities during the week. Whenever the researcher made an appointment with the informants to conduct an interview, observation or focus group interview, oral information was given by telephone, for example the date and time of the day of the appointment. The researcher also asked if they wanted a letter of information and if they would like the researcher to make a phone call the same day or the day before the appointment as a reminder. All of the informants preferred this arrangement of written information and phone call, in case they had difficulties in remembering appointments. All the written information to the informants was characterized by a layman language and did not include concepts not known by the general population (Patton, 2002).

In Study II, the public space was the arena for data collection and ethical issues were elaborated when designing the study and when performing the data collection. For example, considerations were discussed about how the informant would experience the second observer walking behind and observing everything that happened. None of the informants found it to be a problem being interviewed when doing grocery shopping and walking to and from the shop.

The digital recording equipment was another ethical dilemma (Negrón, 2012) in Study II, when the researcher held the equipment in her hand and the conversation was recorded during the observation while doing grocery shopping. In this situation the informants could be regarded as different from an average person doing grocery shopping and their integrity could be threatened. If the conversation in the shop became too personal the researcher changed the subject, and the conversation was elaborated on in the informant's home afterwards.

It was also important that the informants should feel comfortable when doing the grocery shopping together with the researcher in Study II. One informant chose not to go to the shop where he usually shopped when he considered that the staff might identify him as different and needing help in the future if they saw him being accompanied by the researchers. In this case the informant abandoned his familiar shop and chose a shop not so familiar to him. To ensure that the informants were not exposed to harm (Bartlett & Martin, 2001) the researcher intervened when it was obvious that they could not manage situations. This was exemplified when the researcher intervened by giving oral confirmation when the informants asked questions about where to find objects in the shop. The researcher also intervened when it was obvious that the informant's safety was threatened, as in traffic situations (Study II).

The use of photographs and film recordings is common in data collection, but ethical considerations must be addressed (Pink, 2007; Rose, 2007; Spencer, 2011). In this thesis photos and film recordings were used as triggers in the focus groups and were analysed separately. In Study III oral permission from the owner of the shop was obtained before shooting photographs. The photo session was done in the morning before opening time, as the customers' integrity could be threatened if the photos were done when the shop was open.

In Study IV, film recordings were done in public space with the specific focus on traffic situations and people as pedestrians at crossings. One described way to collect data is that the photographers use telephoto lenses or hide themselves from public view when shooting or making film recordings (Spencer, 2011). This strategy was not chosen, as it was considered to be important that the people in public space would see what was going on. The researcher stood behind the zebra crossing, not interrupting the actions at the zebra crossing. In some cases people came to ask what was going on and explanations were given about the interest in people being pedestrians in public space.

Filmed individuals were not in focus in the focus group interviews; attention was rather on the situations and flow of actions. Lately there has been increased attention on the ethical implications of using photo documentation without the agreement or informed consent of the people involved (Spencer, 2011). In Study IV, people with dementia were regarded as the informants included in the study and the people on film recordings were regarded as triggers in the focus groups; therefore we did not inform the persons passing the zebra crossing about the study and did not collect informed consent from them. Furthermore, the individual person him/herself was not in focus in the film sequences. One arrangement for protecting the people's identity at the film recordings was that all the recordings except for one were done in another city than the one where the focus group was performed.

CLINICAL IMPLICATIONS

The findings of this thesis have several clinical implications for occupational therapists and other health care professionals who plan and provide support for people with dementia living in ordinary housing. Findings could also be used in community planning, for example by those who are in positions to influence accessibility and usability aspects in public space for people with cognitive decline.

- Familiar activities and places were important for the informants for doing activities independently. These findings suggest that people with dementia could be supported to do everyday activities in public space frequently and as long as possible in order to maintain their sense of familiarity in places and activities.
- Informants used many different self-initiated actions to meet problematic situations. These findings suggest that occupational therapists and other health care professionals could take into account people with dementias' own actions to meet problematic situations when doing everyday activities in public space, before introducing and teaching new strategies.
- Accessibility was experienced by the informants as constantly changing. These findings indicate that people with dementia may experience specific places as accessible and usable one moment or day but not the next. This suggests that when doing accessibility assessments in public space, for example in grocery shops, it should be taken into account that the outcome of an assessment could vary from day to day. It might therefore be important to assess repeatedly.
- Findings indicate that accessibility in public space may not just concern the space outside the home, but it might also be extended to include the Internet and activities in the home. This suggests that both the home and the Internet could also be taken into consideration when the focus is on accessibility and usability in public space.

- Informants described many different problematic situations and how they met these situations in public space. Findings suggest that community planners and politicians could benefit from a broadened view of accessibility and usability to also include cognitive aspects when regulating public space.

FUTURE RESEARCH

In this thesis informants who still performed activities in public space were included, but we still know very little about the views of those who no longer have access to public space. Moreover, future research could also include families and significant others of people with dementia in order to get their experiences of these issues, e.g. of doing activities together, supporting or letting the persons with dementia do activities on their own in public space. In this thesis, experiences of accessibility and usability among people with dementia living in urban environments, i.e. city centres or suburbs, have been illuminated. However, there is a gap in the knowledge about how people living in rural environments experience accessibility and usability in public space.

Having access to everyday activities in public space was experienced as very important for the informants. However there is a lack of interview questionnaires regarding people's subjective experience of accessibility and usability of public space. Such questionnaires could be developed in future research. To use a combination of objective and subjective assessments in future studies would allow researchers to cover a broad array of accessibility and usability aspects.

In this thesis being a pedestrian was investigated because walking was an important transportation mode. How people with dementia get to different places is a significant aspect of access. However, there is a lack of knowledge regarding how community-dwelling people with dementia experience using public transportation and mobility services, and how they manage problematic situations when using these. This knowledge is important for making public transportation more accessible and usable for all, including people with dementia.

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